Exploring Patient-Centred Care in Saudi Arabia: A Mixed-Methods Investigation from the Perspectives of Diabetic Patients and Healthcare Providers

Reeham Ahmed Alkhaibari, Bachelor of Science (King Abdulaziz University, Saudi Arabia), Master of Science (Kings' College, US)

A thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

Sydney School of Health Sciences

Faculty of Medicine and Health

The University of Sydney

2024

SUPERVISOR'S CERTIFICATE

This is to certify that the thesis entitled "**Exploring Patient-Centred Care in Saudi Arabia: A Mixed-Methods Investigation from the Perspectives of Diabetic Patients and Healthcare Providers**", submitted by **Reeham Ahmed Alkhaibari** in fulfilment of the requirements for the degree of Doctor of Philosophy, is in a form ready for examination.

Signed: _____

Date: February 2024

Pro. Jennifer Smith-Merry

Discipline of Social and Behavioural Science in Health,

Sydney School of Health Sciences,

Faculty of Medicine and Health,

The University of Sydney.

STATEMENT OF ORIGINALITY

I, **Reeham Ahmed Alkhaibari**, hereby declare that the work contained within this thesis is my own and has not been submitted to any other university or institution as a part or a whole requirement for any higher degree.

I, **Reeham Ahmed Alkhaibari**, hereby declare that I was the principal researcher of all work included in this thesis, including work published with multiple authors.

Signed: _____

Name: Reeham Ahmed Alkhaibari

Date: 29 February 2024

DISSEMINATION OF RESEARCH

Papers submitted for publication

Chapters 4 and 5 of the thesis were accepted and published in the journal, *BMC Health Services Research*

- Alkhaibari, R.A., Smith-Merry, J., Forsyth, R. et al. Patient-centered care in the Middle East and North African region: a systematic literature review. BMC Health Serv Res **23**, 135 (2023). https://doi.org/10.1186/s12913-023-09132-0
- Alkhaibari, R.A., Smith-Merry, J. & Forsyth, R. "I am not just a place for implementation. I should be a partner": a qualitative study of patient-centered care from the perspective of diabetic patients in Saudi Arabia. *BMC Health Serv Res* **23**, 1412 (2023). https://doi.org/10.1186/s12913-023-10391-0

Chapter 7 of this thesis has been submitted for publication at the journal, *BMC Health Services Research* and is currently under review *as*

- Alkhaibari, R. A., Smith-Merry, J. Forsyth, R., & Baker, J. " Healthcare providers' views on the provision of patient-centered care in Saudi Arabia"

Conference/symposium presentations

The preliminary findings of Chapter 4 were submitted for presentation as Alkhaibari, R.A., Smith-Merry, J., Forsyth, R., Raymundo, G. Patient-Centered Care in the Middle East and North African region: A Systematic Review at one symposium and two conferences. The preliminary findings were presented by Reeham Ahmed Alkhaibari as follows:

- The 6th Saudi Scientific Symposium in November 2021, as a virtual poster.

- The 5th International Conference of Innovative Studies of Contemporary Sciences is in January 2022, as an oral presentation.
- The University of Sydney, Faculty of Medicine and Health HDR conference July 2022, as an oral presentation.

The findings of the Chapter 5 were submitted for presentation as Alkhaibari, R.A., Smith-Merry, J., Forsyth, R. "I am not just a place for implementation. I should be a partner": A qualitative study of patient perceptions of their involvement in care in Saudi Arabia. The findings were presented by Reeham Ahmed Alkhaibari as follows:

- The 23rd International Conference on Integrated Care (ICIC23) May 2023, as a digital poster presentation.

Awards

- The PhD candidature of Reeham Ahmed Alkhaibari was supported by *the Saudi Arabian Cultural Mission* Scholarship in Australia.
- The candidate was also awarded the following funds during the PhD candidature:
- The Faculty of Medicine and Health funding which was provided by the University of Sydney to support research costs related to a Higher Degree by Research student's study. The faculty funding was received annually three times during the candidature.

DEDICATION

This thesis is dedicated wholeheartedly to my beloved mother and late father, who have been my strongest pillars of support throughout my academic journey. Their unwavering encouragement and endless sacrifices have been invaluable, and I am eternally grateful for their unwavering belief in me. Their love and guidance have shaped me into the person I am today, and this thesis is a testament to that.

ACKNOWLEDGMENTS

I am deeply grateful to everyone who contributed to the successful completion of this thesis. This journey has been challenging and rewarding, and I could not have reached this milestone without the support, encouragement, and guidance of numerous individuals and institutions. In this acknowledgement, I express my heartfelt gratitude to each of them.

First, I humbly acknowledge the divine blessings of Allah, the Almighty, which gave me the strength and courage to complete this thesis, especially during these unprecedented times of the COVID-19 pandemic. His blessings have played a significant role in helping me overcome the challenges I faced throughout this journey.

Foremost, I would like to express my deepest gratitude to my primary supervisor, Professor Jennifer Smith-Merry, for her unwavering support and dedication in providing me with a productive working environment. Her guidance and encouragement have been instrumental in ensuring that I had a productive and fulfilling PhD journey, which has been a driving force behind this accomplishment. Moreover, she went out of her way to connect me with other PhD students to network, especially during the lockdown period when socialising was challenging, particularly for a new international student like me.

I cannot express enough gratitude for having Dr Rowena Forsyth as my secondary supervisor. Her infectious enthusiasm and unwavering support have been the cornerstone of my research journey. Her constructive criticism and feedback have helped me grow as a researcher and become who I am today. I also want to express my heartfelt gratitude to Dr. Jannah Baker, who served as my other primary supervisor. Her extensive knowledge and expertise in statistics were immensely valuable to me throughout my academic pursuit. She was always

available to discuss statistical concepts with me, and her guidance was instrumental in helping me complete this milestone.

I also want to acknowledge the support of Taif University and the Ministry of Higher Education in Saudi Arabia, who provided me with the financial support to pursue my Ph.D. With their help, I was able to achieve this milestone.

Additionally, I want to express my sincere gratitude to my friend Gianina Marie Raymundo. Her support, dedication, and expertise have been invaluable in completing my thesis. She spent countless hours discussing with me, sharing her knowledge, organising "shut up and write" sessions, and serving as a co-author in chapter 4 of the systematic review. Working with her has been an absolute pleasure.

My gratitude extends to the faculty members and researchers who have contributed to my academic journey. Their dedication to knowledge dissemination and intellectual curiosity has been a constant source of inspiration. I am thankful to my university and its staff for providing an excellent environment for research and education. The facilities, resources, and opportunities provided have been instrumental in shaping my academic pursuits.

I am incredibly grateful to my colleagues at the University of Sydney, including Qamra Muaikel Alqahtani, Naif Qasem T Aljabri, and Prakash Dhopte. Our stimulating conversations, constructive feedback, and shared experiences have helped me grow personally and professionally, making this journey more enjoyable and memorable. Additionally, I would like to express my heartfelt appreciation to my friends and colleagues in Saudi Arabia who have offered their unwavering emotional support.

I want to express my heartfelt gratitude to Professor Abdulellah Al Thobaity, Professor Naif Alotaibi, Professor Mohamad Almakki, Dr Amal Alsofiani, Miss Wafaa Althubaiti and Miss Mona Alqurashi for their invaluable support in the data collection phase of this thesis.

I am grateful to all the participants who volunteered their time for the research conducted in this thesis. Their willingness to contribute has been crucial in shaping the findings and conclusions of this work.

My family deserves special recognition for their unwavering belief in me. Their constant encouragement, love, and understanding have been my pillars of strength throughout this endeavour. I am eternally grateful for their sacrifices and unconditional support.

Finally, I want to acknowledge that the title of this thesis has been updated from "How Can Patients Contribute to Developing the Healthcare System in Saudi Arabia?" to "Exploring Patient-Centred Care in Saudi Arabia: A Mixed-Methods Investigation from the Perspectives of Diabetic Patients and Healthcare Providers". I also would like to acknowledge that for the purpose of publication, some of the chapters in this thesis follow Australian spelling (Chapters 1, 2, 3, and 8), while others use American spelling (Chapters 4, 5, 6, and 7). Additionally, I would like to acknowledge the use of Grammarly software as an editing tool to enhance my work's academic language and accuracy.

COVID -19 IMPACT STATEMENT

In this section, I will briefly discuss the impact of Covid-19 on the progress of this thesis.

Firstly, the initial plan for this thesis was to conduct a sequential exploratory research design. However, due to the COVID-19 lockdown, we realised that this method would be time-consuming, and therefore, we decided to switch to a concurrent mixed-method approach, which would be more efficient.

Second, the original plan was for the student investigator to travel to Saudi Arabia and recruit diabetic patients from a single hospital. However, due to travel restrictions, the student was unable to travel and had to switch to online recruitment.

Thirdly, the initial aim of the study was to evaluate the perception of healthcare providers working in a diabetic centre towards the practice of patient-centred care in a single hospital. However, we modified the plan to include all providers working in a single hospital due to a low response rate. After nine months, we stopped the recruitment process upon receiving responses from 116 healthcare providers who completed the online questionnaire.

Fourthly, for the qualitative study, we initially planned to conduct the interviews in a private room at the hospital. However, due to Covid-19 restrictions and the need for social distancing, we had to change our interview method to telephone interviews. This change resulted in fewer participants being recruited than our initial plan.

THESIS ABSTRACT

Introduction

Patient-Centred Care (PCC) is a fundamental principle in global healthcare systems, and known for its association with positive health outcomes, such as improving patient knowledge and reducing unnecessary referrals. As the government of Saudi Arabia shifts towards adopting a PCC approach in healthcare, there is a crucial need to understand its implementation. However, current research on the practice of PCC in Saudi Arabia remains limited. This thesis presents a thorough investigation of the practice of PCC in the Middle East and North African region (MENA), exploring the perceptions of people living with diabetes and healthcare providers towards PCC in the Saudi Arabian context. The study aims to provide valuable information to inform policies that guide the implementation of PCC in Saudi Arabia.

The study seeks to address the following research questions:

- What is the current form of patient involvement in healthcare practice in Saudi Arabia?
- How do healthcare providers enable and empower patient involvement in health encounters?
- What model is most appropriate for improving patient involvement in practice in Saudi Arabia?

Methods

A systematic review of fifty articles on the practice of PCC in the Middle East and North African (MENA) region was conducted (Chapter 4). This influenced the development of the

project data collection which comprised of two surveys and semi-structured interviews. Interviews with people living with diabetes (three females, four males) examined patient perceptions of their involvement during their interactions with healthcare providers (Chapter 5). Thematic analysis was applied to identify the key themes. An online survey of 116 diabetic patients (56 women, 60 men) investigated their perceptions of their interactions with their healthcare providers (Chapter 6). Finally, a self-reported questionnaire with 116 healthcare providers (109 nurses, 7 physicians) examined healthcare providers' understanding and self-reported implementation of PCC (Chapter 7). In both Chapter 6 and 7, quantitative analysis was conducted using statistical tools, including descriptive statistics, Student's t-tests, analysis of variance tests, and correlation analysis, to assess the perspectives of both patients and healthcare providers on PCC implementation in Saudi Arabia.

Results

The published systematic review results highlighted that there are certain principles of patient-centred care are being implemented in the MENA region, such as treating patients as individuals, demonstrating empathy, and engaging in effective communication. The study also showed a variation between patient and healthcare provider perspectives on the way in which patient-centred care is practised. The study also highlighted the factors that uniquely influence the practice of PCC in the region. The central finding of the review was that the healthcare system in the MENA region is influenced by culture, which has a great impact on PCC practice with greater emphasis on family involvement in care rather than individual patient involvement. More importantly, the study reported that there is support for the concept of PCC in the region, but the practice of PCC in delivering healthcare is still limited.

The results of the qualitative study found that individuals living with diabetes had limited knowledge of patient involvement in care and that the willingness of the patient to participate

in decision-making in care was affected by the type of involvement asked of them (e.g., patients preferred to have a minimal role in their care and mostly rely on the expertise of the healthcare provider expertise for decision-making). The study also identified barriers that impact patient involvement in care (e.g., lack of professional ethics, poor patient engagement, and lack of empathy). It also unveiled the patient's empathy for healthcare providers, demonstrating their understanding of the intense work pressures associated with the healthcare environment. Finally, the study highlighted the impact of culture on PCC practices in Saudi Arabia, demonstrating that PCC practice is influenced by gender norms, and the role of the family in care.

Patients' participants in the quantitative study reported that they experienced PCC to some extent when interacting with healthcare providers, as they rated PCC 63 out of 80 on average on the Patient Provider Interaction Questionnaire (PPIQ). The study reported that patients receiving care in the western region had a significantly higher overall mean PCC score and scores for all PCC subscales- *effective communication*, *interest in patient agenda*, empathy and *patient involvement in care* than patient receiving care in other regions of the country. The study examined different aspect of PCC, of which *effective communication* and *interest in patient agenda* received the highest rating with mean score of (16.3 and 15.9) out of 20, respectively. While *empathy* and *patient involvement in care* received the lowest rating 15.6 and 15.3, respectively. Nevertheless, the analysis of the open-ended question responses provided evidence that patients lack awareness of the potential for a greater role in care. Some patients believed that their role in care is restricted to complying with the healthcare provider views rather than interacting with them and negotiating the best treatment options with the healthcare provider.

The results of the quantitative study with healthcare providers revealed that they perceived themselves as effective in practising PCC, with an overall mean PCC score of 72 out of 80 on average on the Patient-Provider Relationship Questionnaire (PPRQ) The study evaluated different aspects of PCC, of which *effective communication* received the highest rating with a mean score of 18.5 out of 20. Showing *interest in the patient's agenda* was rated second highest, with a mean score of 18.1. Both *empathy* and *patient involvement in care* received the lowest ratings, each having a mean score of 17.8. However, the qualitative analysis of the responses to two open-ended questions presented a contrasting perspective. These findings indicated that healthcare providers' knowledge of the term PCC was inconsistent with the definitions in existing literature on the subject. Despite this lack of comprehensive understanding of the dimensions and practices of PCC, healthcare providers did acknowledge the value and significance of PCC. They recognised that implementing PCC practices positively impacted patients' health status, and that this led to benefits such as reducing unnecessary medical procedures.

Discussion and Conclusion

This thesis, focussing on the perspectives of diabetic patients and healthcare providers, extends our understanding of the nature of patient-centred care practices in Saudi Arabia. It identifies the key factors influence the implementation of PCC, including both barriers and facilitators. Among the barriers are family involvement, lack of empathy, long waiting time and cultural norms, which can hinder the effective implementation of PCC. Conversely, facilitators include elements like effective communication, empathy, and allocation of sufficient time to interact with patients, which promote and support the practice of PCC. Furthermore, the study also assessed the level of awareness of the concept of PCC and its practice from the perspective of both patients and healthcare providers. The evident lack of

awareness among these groups regarding patient involvement in care underscores the necessity for ongoing education and training. These initiatives should be extended to both patients and healthcare providers to effectively implement the ideal PCC approach. Additionally, the establishment of a patient advocacy group could play a crucial role in educating patients about the possibilities of taking on an active role in their own care, thus promoting and improving the practice of PCC in the country.

This research highlights the need for the Ministry of Health in Saudi Arabia to advocate for actively promoting community involvement in the strategic planning and formulation of PCC policies. The involvement of the community is important for cultivating a comprehensive understanding of the healthcare needs specific to the region and, thereby, achieving improved healthcare outcomes. Moreover, the study underscores the necessity of formulating a culturally relevant definition of PCC tailored to the Middle East and North African context. Such a definition should encompass the religious and familial dynamics that significantly shape patients' health perceptions and their interactions with healthcare providers.

The thesis proposes a definition of patient-centred care along with a framework that outlines the factors influencing the practice and effective delivery of PCC that is specific to the MENA region, with a particular focus on Saudi Arabia. The proposed definition and framework focus on establishing a therapeutic relationship between patients and healthcare providers while taking into account important cultural factors such as family involvement, gender roles, and the perceived social status of healthcare providers. These factors play a crucial role in providing care that meets the unique needs of patients in the region. Therefore, to achieve better healthcare outcomes for patients, it is imperative for policymakers and researchers in Saudi Arabia and beyond to confidently adopt the proposed model to identify

ways to improve the implementation of PCC and ensure better healthcare outcomes for patients.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

CHAPTER 4

CHAPTER 8

CHAPTER 1

INTRODUCTION

Introduction

Many healthcare systems worldwide have undergone a transformation from the traditional model of care, where healthcare providers make decisions on behalf of their patients (Komrad, 1983; Lazcano-Ponce et al., 2020), to a more patient-centred approach. This shift has occurred in response to ethical consideration of the role of the patient in relation to their own health car and practical evidence which has shown the impact of paternalistic communication styles on patient health (Taylor, 2009). A patient-centred approach emphasises improving access to healthcare information to empower individuals to be fully-informed so as to improve their decision-making and healthcare experience (Byrne et al., 2020; Gardiner, 2008). Patient-centred care (PCC) is an essential aspect of healthcare that emphasises establishing collaborative partnerships between healthcare providers, patients, and families in the planning, delivery, and evaluation of healthcare services (Institute of Patient and Family Centered Care, 2021). It is a model which defines the role of the patient as central within the effective operation of the healthcare system and guides approaches used to provide care in relation to this (Byrne et al., 2020; Han, 2016; Luxford et al., 2010). To implement PCC, various initiatives and strategies have been introduced, such as the implementation of patient rights-based charters, soliciting patient feedback, and involving patients in safety improvement efforts (Australian Commission on Safety Quality in Health Care, 2011). These initiatives have been influenced by practices in European and Western countries and are being taken up by the World Health Organization (WHO), indicating the

global recognition of the importance of PCC in improving healthcare services.

In the face of an increasingly aging population and a rising prevalence of chronic illnesses, adopting an approach that centres on the needs of patients and their families can aid the healthcare system in offering the necessary support and enhancing the quality of life for both patients and their families (Kokorelias et al., 2019). Grilo et al. (2017) emphasise the necessity of implementing a PCC approach to managing chronic illnesses. This approach would empower patients to be actively involved in managing their health, resulting in enhanced overall well-being and satisfaction with care (Cramm & Nieboer, 2016). Previous research has yielded promising results in the context of introducing PCC in order to enhance health outcomes for individuals living with chronic illness. Research by Kuipers et al. (2019) and McMillan et al. (2013) shows that the implementation of PCC would improve the well- being and satisfaction of patients living with chronic conditions. Ulin et al. (2015) argue that PCC not only enhances patient well-being but also reduces healthcare costs, decreases uncertainty concerning illness and recovery, improves patient dignity, more effective treatment, and advancements in healthcare systems.

Patient-centred care in the MENA region and Saudi Arabia

The practice and accompanying academic literature on PCC has experienced considerable expansion since the Institute of Medicine declared PCC as one of the six key elements of the quality of care in 2001 (Berghout et al., 2015; Epstein & Street, 2011; Institute of Medicine, 2001; Vennedey et al., 2020), leading to the WHO creating guidelines and resolutions for healthcare delivery in all its regions. These guidelines emphasise the importance of adopting the perspectives of individuals, carers, family members, and communities. In 2007, the WHO issued a resolution endorsing a policy framework that member states can use to create and execute healthcare policies and interventions that prioritise the needs of people while taking

into account their unique national circumstances (World Health Organization, 2007, 2016).

However, despite the substantial expansion of the literature on PCC, many of the frameworks that have been published have failed to consider or reflect the cultural norms of the Middle East (Jayadevappa & Chhatre, 2011; Mead & Bower, 2000; Scholl et al., 2014). For example, Carman et al. (2013) have suggested a patient and family engagement framework that outlines various levels of patient engagement, ranging from consultation to partnership and shared leadership, spanning from direct care to policymaking. The framework recognises the influence of social norms on how patients perceive their ability to contribute to their care. However, the specific cultural norms impacting patient perception in the Middle East remain unclear. The only existing framework to address this, is Webair's (2020) adaptation of the four-level model of PCC in the healthcare system (patient, healthcare provider, organisation and environment) proposed by Ferlie and Shortell (2001). Webair's (2020) proposed model emphasises the importance of incorporating cultural, familial, and religious factors into patient-centred care models in the Middle East. This model suggests that involving patients and their families in all of the health system areas suggested by Ferlie and Shortell (2001) and tailoring care to their needs can enhance the quality of health services. However, the model is limited because it is a theoretical model which has not been explored in studies with patients or practitioners.

Studies conducted in Middle East and North African (MENA) region have shown support for actively involving patients in the decision-making process regarding their healthcare journey (Akkafi et al., 2019; Al-Tannir et al., 2017; Alhaqwi et al., 2016; Cheraghi et al., 2017; Schattner et al., 2006). However, it is crucial to acknowledge that existing studies on PCC in the MENA region have predominantly relied on a PCC definition rooted in Western culture, neglecting a comprehensive Middle East-specific interpretation of PCC that considers the

cultural and religious values intrinsic to the region (Webair, 2020). The cultural and societal differences between Western and MENA cultures are substantial, which suggests that the practice of PCC would diverge significantly in these regions due to differences between their individualistic and collectivist based cultures, as well as the different power dynamics prevailing within their societies. This divergence will be explored more extensively in the following chapter.

Saudi Arabia, like many other countries, has recognised the significance of enhancing healthcare services to make them more responsive to patient needs. In 2019, the Saudi government expressed a keen interest in transitioning and reforming the existing healthcare system, which had traditionally been centred around staff and resources, to one that is patient or person-centred (Al-Sahli et al., 2021; Ministry of Health's Vision Realization Office, 2019). Despite these intentions, research indicates that there is still a substantial journey ahead to effectively implement the ideal PCC in Saudi Arabia. This gap can be primarily attributed to the limited understanding of healthcare providers regarding the patient-provider relationship (Woodman et al., 2022) and the inadequate awareness among patients about their rights in healthcare (Almoajel, 2012).

This current thesis responds to this by providing important data about the contemporary practices of PCC in Saudi Arabia. It does this by examining the perceptions of both patients and healthcare providers regarding patient involvement in care in Saudi Arabia and identifying factors that can influence the effective implementation of PCC. The following section provides contextual information about Saudi Arabia, including its demographic and economic background, as well as an overview of the Saudi healthcare system. Following this section, I will provide an introduction to the research questions which structure the research reported in this thesis and detail the thesis structure.

Saudi Arabia

Demographic and Economic Background

Saudi Arabia, situated in the Middle East, is the largest country in the region, spanning over 2.149 million square kilometres (850,000 square miles). Geographically, it is positioned on the Arabian Peninsula, bordered by the Arabian Gulf and the Red Sea to the west and northeast, respectively. The country shares its northern borders with Jordan, Kuwait, and Iraq, while Qatar, the United Arab Emirates, and Bahrain lie to the east. Additionally, it shares its southern borders with Yemen and the Sultanate of Oman (Albejaidi, 2010; Mufti, 2000). Saudi Arabia is administratively divided into thirteen regions, as depicted in Figure 1. It is notable for being home to the two holiest sites of Islam: Mecca and Medina. Islam is the predominant religion in the country, and Arabic is the national language.

Figure 1. The 13 administrative regions of Saudi Arabia (Source: Ibrahim et al. (2021))

The discovery of oil in Saudi Arabia in 1938 has had a profound impact on the country's economy, leading to significant development and establishing it as one of the wealthiest and most rapidly advancing nations in the Middle East (Mufti, 2000). The country holds

the distinction of being the largest producer and exporter of oil globally, possessing substantial oil reserves that contribute to approximately 25% of the world's total oil supply (Mufti, 2000). This remarkable progress has influenced cultural, social, and economic dimensions of Saudi Arabian society.

Population

In recent decades, Saudi Arabia has experienced a notable increase in its population. By the year 2021, the population had reached a total of 34 million people, which is a growth of 16.8%, compared to 29.1 million in 2012 (Ministry of Health, 2021). The Ministry of Health (MoH) in Saudi Arabia reported an annual population growth rate of 2.38% (Ministry of Health, 2021). Saudi Arabia has a total fertility rate of 1.9% and approximately 24.5% of the population is under the age of 15, while the population between the ages of 15 and 64 has risen from 59.8% in 2005 to 72% in 2021 (El-Khoury, 2009; Ministry of Health, 2021). The percentage of the population aged 65 years or older is 3.5% and the life expectancy at birth increased from 73.7 years in 2010 to 75 years in 2018. The infant mortality rate has significantly declined from 16.9 deaths per 1000 live births in 2010 to 6 deaths per 1000 live births in 2018 (Ministry of Health, 2021). The Gross Domestic Product (GDP) per capita has also grown from US$23,311 in 2021 to US$20,263 in 2016 (Ministry of Health, 2021). These data reflect positive trends in population growth, improvements in life expectancy, a reduction in infant mortality rates, and an increase in GDP per capita. These indicators signify advancements in healthcare, economic development, and overall living conditions in Saudi Arabia. But they have also caused changes to the pattern of disease and resulting changes to the health care sector which have necessitated a consideration of new ways of operating.

Healthcare Burdens in Saudi Arabia

Saudi Arabia continues to face persistent healthcare challenges. While the government has successfully controlled and improved child and maternal mortality rates and reduced communicable diseases, noncommunicable diseases (NCDs) remain a significant concern in the country (Ministry of Health's Vision Realization Office, 2019). According to the World Health Organization's Noncommunicable Diseases Progress Monitor 2020, 73% of total deaths in Saudi Arabia are attributable to NCDs (World Health Organization, 2020). This was consistent with a previous report from 2018, which indicated that cardiovascular diseases accounted for 37% of total deaths, followed by cancers (10%), chronic respiratory diseases (3%), diabetes (3%), and other NCDs (20%) (World Health Organization, 2018).

Due to lifestyle changes, the prevalence of diabetes among the Saudi population aged 20-79 years was reported to be 17.7% in 2021 (International Diabetes Federation, 2021) which is significantly higher compared to 13.2% in 2013 (Ministry of Health, 2013b). In 2023, a national study revealed an estimated hypertension prevalence of 9.2% among Saudis aged 14 years and older (Alenazi & Alqahtani, 2023). Furthermore, the 2019 Saudi Arabia World Health Survey reported overweight and obesity prevalence rates of 38% and 20% respectively among individuals aged 18 years and older (Ministry of Health, 2019). There has also been a noticeable increase in the number of years lived with disability caused by mental disorders, substance abuse, neurological disorders, and cancer. Consequently, between 2010- 2017, there was a change in the patterns of disability-adjusted life years in Saudi Arabia. over this period cardiovascular disease maintained its position as the primary cause of disability, followed by musculoskeletal disorders, transport injuries dropped from the third to fifth position, and cancer increased to third highest cause of disability (Tyrovolas et al., 2020). In addition, the continuous population growth - particularly within the 60-79 age group, which is projected to reach 4.63 million by 2030 - has led to increased demand for and burden on healthcare services (Ministry of Health's Vision Realization

Office, 2019). The data presented here indicates that the Saudi healthcare system faces challenges due to the growing prevalence of NCDs and the large proportion of elderly citizens, leading to a higher demand for care. These demographic changes and growing healthcare burdens in recent years have resulted in the need for increased healthcare expenditure and the Saudi government has demonstrated a strong commitment to enhancing healthcare services and population health within the country. According to the Saudi Central Bank's Fifty-Seventh Annual Report, the government allocated 174.7 billion Saudi Riyals (SR) ($US45.5 billion) for the health services and social development sectors in 2020. This allocation represents 17.6% of the total budget and reflects a 4.6% increase compared to the previous year's budget (Saudi Central Bank, 2021).

Saudi Healthcare System

Before the discovery of oil in the 1930s there was a lack of standardised healthcare systems or formal health services (Albejaidi, 2010; Mufti, 2000). During that time, people relied heavily on traditional medicine and lived without access to modern healthcare services (Ghaznawi, 1986; Mufti, 2000). Traditional medicine in Saudi Arabia is associated with religious beliefs, and individuals often seek remedies and treatments based on their faith. Examples of traditional remedies include holy Quran therapy, the use of honey, black seeds, and Alhjama (cupping) (Alrowais & Alyousefi, 2017). A recent study indicated that a significant percentage of the population in Saudi Arabia still relies on traditional medicine (Alrowais & Alyousefi, 2017). This implies that traditional medicine continues to influence the healthcare choices of individuals in Saudi Arabia despite the development of the modern healthcare system and the availability of conventional medical treatments.

The Saudi government has undertaken significant efforts to standardise and modernise the

healthcare system in the country. These efforts began in 1926 with the establishment of the Health Department, which aimed to organise healthcare services in the country. In 1927, the department's name was changed to the General Directorate of Health and Aid, reflecting a renewed focus on improving healthcare services and disease control in Saudi Arabia. This led to the creation of directorates of health affairs in different regions of the country (Albejaidi, 2010; Mufti, 2000). The Ministry of Health (MoH) was established in 1954, marking a major milestone in the transformation of the healthcare sector (Albejaidi, 2010; Mufti, 2000). The MoH is recognised as the primary healthcare provider in Saudi Arabia and has played a pivotal role in the dissemination of health services nationwide (Al-Hanawi et al., 2019; Alatawi et al., 2020; Albejaidi, 2010; Almalki et al., 2011). Its responsibilities include strategic planning, policy formulation, supervision, and monitoring of all health programs in the country (Al Yousuf et al., 2002). The region-based directorates, on the other hand, are tasked with implementing approved programs and policies in collaboration with the MoH. They also share responsibility for public and private hospitals within their respective provinces (Alraga, 2017).

In 1970, the Saudi government introduced the first Five-year Development Plan, which aimed to enhance and expand health services, increase the healthcare workforce, and improve policies for future development (Mufti, 2000). This plan played a crucial role in revolutionising primary, secondary, and tertiary levels of care (Rahman & Al-Borie, 2021).As a result of these efforts, by 2000 the Saudi healthcare system had achieved significant recognition from the World Health Organization, ranking 26th among 190 countries in health system performance, surpassing developed nations such as Canada (30th), Australia (32nd), and the United States of America (37th) (Almalki et al., 2011; Jannadi et al., 2008; Tandon et al., 2000).

Major Health Providers in Saudi Arabia

In Saudi Arabia, healthcare services are provided to citizens free of charge as mandated by the country's constitution, specifically Article 31, which obliges the government to offer healthcare services to all citizens who seek treatment in public hospitals (Albejaidi, 2010). Services provided by the MoH account for approximately 60% of the services in Saudi Arabia. The remaining 40% of healthcare services are shared between the private sector and semi-government sectors (Al Asmri et al., 2020; Alatawi et al., 2020; Alraga, 2017; Sebai et al., 2001). At present (2023), there are a total of 497 hospitals in the country. The majority of these hospitals, approximately 287, fall under the MoH and collectively provide 45,330 beds. Additionally, there are 159 private hospitals with a combined capacity of 17,889 beds, along with 51 hospitals operated by other governmental sectors, offering a total of 14,005 beds (Ministry of Health, 2021).

The MoH has responsibility for overseeing both public and private healthcare facilities (Albejaidi, 2010) but primarily operates and provides services within the public sector (Alatawi et al., 2020). The private healthcare sector is composed of companies that own and operate healthcare facilities, offering services for a fee that can be covered by employers, insurers or paid out of pocket by individuals (Jannadi et al., 2008; Khaliq, 2012). The semi- government sectors in Saudi Arabia consist of specialised hospitals, such as the King Faisal Specialist Hospital and Research Centre, Security Force medical services, National Guard Health Affairs, the hospitals affiliated with the Ministry of Higher Education, the hospitals of the Arabian American Oil Company, and the health services provided by the Royal Commission for Jubail and Yanbu, and the Red Crescent Society (Alraga, 2017). These agencies primarily provide healthcare services to specific populations, including their employees and their families, except for the Ministry of Higher Education hospitals and Red Crescent Society, which offer services to a broader range of individuals (Alraga, 2017).

Levels of Care in the Saudi Healthcare System

In Saudi Arabia, the provision of health services is organised into four distinct levels: primary, secondary, tertiary, and medical cities (Al Asmri et al., 2020; Al Yousuf et al., 2002; Almalki et al., 2011; Jannadi et al., 2008; Sebai et al., 2001). The primary level of health services focuses on delivering comprehensive care that includes preventive, curative, and promotive health services. This level serves as the initial point of contact for individuals seeking healthcare. When patients require more specialised care, they are referred to the secondary level. The secondary level comprises general and peripheral hospitals that offer a range of diagnostic and curative services. These hospitals typically have emergency departments, outpatient departments, facilities for minor surgeries, and provisions for hospitalisation. If patients require further specialised care, they are then referred to the tertiary level. At the tertiary level, central hospitals provide advanced medical services, including surgical interventions and rehabilitation. These hospitals offer a higher level of expertise and specialised care compared to general hospitals. Lastly, medical cities represent the fourth level of the healthcare system. These medical cities provide specialised health services, functioning as research facilities and teaching centres within the country.

Healthcare Reform in Saudi Arabia

Saudi Arabia has historically relied heavily on oil revenue, which has played a significant role in funding the provision of free public services to its population. However, recent challenges have emerged which make it increasingly difficult to sustain the provision of these services at no cost. These challenges include the soaring cost of healthcare services, a decline in oil revenue, changes in the demographic makeup of the population (including increases in life expectancy and sedentary lifestyles, leading to shifting disease patterns),

rising consumer expectations, and ineffective management practice in the provision of healthcare services (Rahman & Alsharqi, 2019). This ineffectiveness is evident, for instance, in insufficient primary care, the uneven distribution of tertiary hospitals across the nation, and unwarranted disparities in healthcare provision. There is also a substantial issue with the quality of services provided, which can be attributed to inadequate protocols and pathways for treatment, as well as incomplete measurement of patient processes and outcomes (Ministry of Health's Vision Realization Office, 2019).

As part of its reform efforts, the Saudi government has implemented a range of initiatives aimed at improving the healthcare sector. One notable initiative introduced in 2020 is the Transformational Plan Program For The Health Sector, which seeks to restructure the healthcare system for individuals residing in or visiting Saudi Arabia (Health Sector Transformation Program, 2021). In this plan the government committed to enhancing health and quality of life, improving healthcare services, and increasing the accountability of healthcare organisations and staff in providing safe, effective, patient-centred, timely, and equitable care. It also committed to improving the value of care by managing costs and improving outcomes (Ahmad et al., 2020; Al-Sahli et al., 2021). The Health Sector Transformation program, launched in 2021 as part of the Vision 2030 initiative, aims to restructure the healthcare sector into a holistic, efficient, and integrated system that prioritises the health of both individuals and society (Alasiri & Mohammed, 2022; Ministry of Health's Vision Realization Office, 2019).

In 2016, the government recognised the need for improvement and pursued healthcare privatisation as a potential solution (Sama'a et al., 2021). By investing in the healthcare sector through state and private funds, the government aims to promote efficiency, quality, and population satisfaction in healthcare provision while fulfilling its public

responsibilities (Rahman, 2020; Rahman & Al-Borie, 2021). The goals of privatising healthcare services in Saudi Arabia are multi-faceted. They include reducing the country's budgetary strain and increasing revenue, encouraging competition, improving efficiency and transparency, attracting both local and foreign investments, diversifying involvement in new sectors, and creating employment prospects. The overall aim is to enhance quality, lower service costs, and achieve greater effectiveness in the healthcare system (Almutairi & Al Shamsi, 2018). Consequently, the implementation of privatisation is carried out through health clusters (Sama'a et al., 2021), which serve as integrated administrative health systems comprising a consortium of healthcare providers dedicated to meeting the healthcare needs of a population of approximately one million individuals in specific geographic locations (Health Sector Transformation Program, 2021). These health clusters encompass primary care centres, general hospitals, and specialised services, forming a comprehensive network of healthcare facilities and resources. Their primary objective is to facilitate flexible care delivery and ensure prompt service provision, ultimately enhancing consumer satisfaction (Health Sector Transformation Program, 2021).

Furthermore, the implementation of privatisation grants a certain level of independence to health clusters and hospitals, fostering a collaborative partnership between the public and private sectors (Alasiri & Mohammed, 2022). At present, the MoH has established two healthcare clusters, namely the Riyadh Health Cluster and the Health Cluster in the Central Region (International Trade Administration, 2022). These health clusters are financed by the Centre for National Health Insurance through tailored payment frameworks that align with the specific requirements of each cluster. The establishment of these payment structures relies on precise national census data and the implementation of internationally recognised best practices (Health Sector Transformation Program, 2021).

The new Model of Care (MOC) was introduced by the MoH in 2017 (Chowdhury et al., 2021; Ministry of Health's Vision Realization Office, 2019). One of the core themes of the MOC serves as a fundamental cornerstone for enhancing treatment and care approach at the individual level (Ministry of Health's Vision Realization Office, 2019). The implementation of this model actively fosters public health promotion, prioritises preventive measures, enhances health awareness throughout society (Chowdhury et al., 2021) and ensures timely and appropriate delivery of care to individuals by the most suitable healthcare team in the most appropriate setting (Alomari et al., 2021). The model has been developed with a foundation built upon several principles including empowering individuals and their family members to enable them to take control over their own health (Health Sector Transformation Program, 2021; Ministry of Health's Vision Realization Office, 2019). The model delivers care across six systems that prioritise the needs of patients across their lifespan. These systems, known as "Keep well", "Safe birth", "Planned care", "Urgent care", "Chronic conditions" and "Last phase," emphasise the promotion of physical, mental, and social well- being of individuals (Ministry of Health's Vision Realization Office, 2019), as depicted in Figure 2. To ensure that healthcare providers understand the new Model of Care and how it should be practised, the Saudi Commission for Health Specialists has developed an online program for healthcare providers to familiarise themselves with the key concepts of the new Model of care (Saudi Commission for Health Specialists). These are represented in the Figure below.

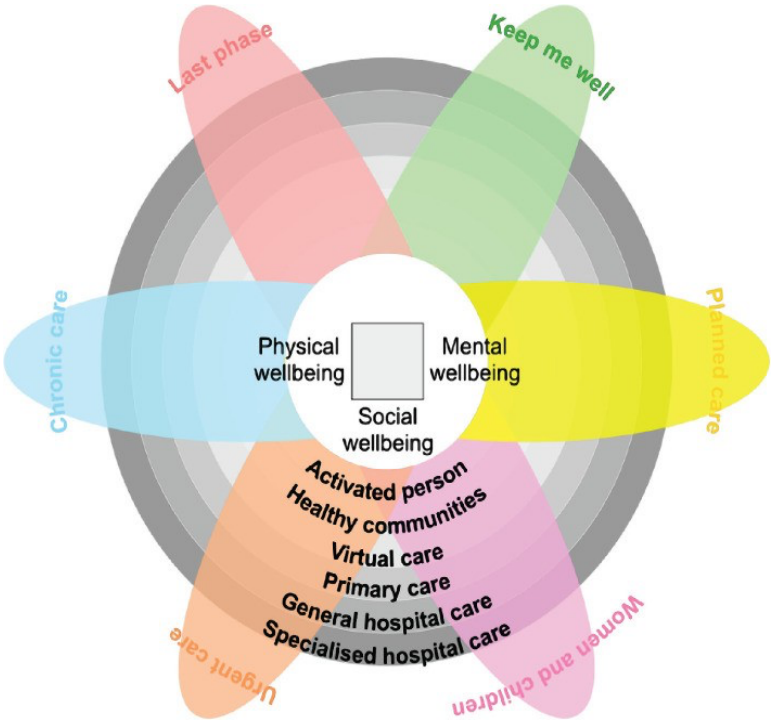

Figure 2. The Model of Care (Source Ministry of Health's Vision Realization Office (2019))

Healthcare workforce

The healthcare system in Saudi Arabia has experienced remarkable growth since 1950, when it had 111 physicians and fewer than 1,000 hospital beds (Mufti, 2000). This expansion in the number of hospitals discussed earlier, has resulted in a significant transformation of the healthcare workforce. As of 2021, the total number of physicians, including dentists, had reached 122,356, with Saudi physicians representing only 40% of the overall number of physicians. Most of the health workforce, therefore, comes from overseas. For example, the nursing and midwifery profession comprises 201,489 individuals, of which 43% are Saudi, there are 30,840 pharmacists, 39% of whom are Saudi, and 131,003 allied health professionals, with 81% being Saudi (Ministry of Health, 2021).

Medical Education and Training in Saudi Arabia

Throughout the past century, higher education has remained a significant priority within the

Kingdom of Saudi Arabia (Al-Sulaiman, 2000) and sits alongside the Saudi government's interest in enhancing and transitioning towards a contemporary healthcare system. This commitment is exemplified by the government's provision of scholarships to Saudi citizens holding high school diplomas, enabling them to pursue medical and allied health studies abroad (Telmesani et al., 2011). Within Saudi Arabia, medical education has undergone two distinct phases. Initially, until the early 2000s, the prevailing approach in medical education followed a traditional curriculum, spanning up to seven years of study. This curriculum encompassed a 6-year program comprising 3 years dedicated to basic and medical science courses, followed by 3 years of clinical training, culminating in a 1-year internship (Telmesani et al., 2011). This traditional model was implemented in all medical colleges across the country, including those at King Saud University, King Abdul-Aziz University, King Faisal University, King Khalid University, and Umm Al-Qura University. However, this approach relied on a teacher-centred paradigm, which consequently introduced constraints in facilitating students' learning experiences. This approach centralises the instructor as the authoritative figure responsible for dispensing knowledge to the student, who is perceived as a novice or empty vessel awaiting the infusion of knowledge, with the teacher being responsible for determining the sequence, method, and pace of learning (Kasim, 2014). It is characterised by a congested curriculum that relies heavily on extensive lectures as the primary method of information delivery, often tied to individual courses with objectives more aligned with the priorities of specific departments, disciplines, or specialties rather than addressing the actual needs of the community (Al-Sulaiman, 2000; Shawky & Soliman, 2001) Concerns regarding the constraints of the conventional curriculum became increasingly prominent, resulting in heightened demands for reform within the Saudi medical community.

In response, the Ministry of Higher Education assumed a leading role in enhancing education, specifically focusing on medical education. As a result, in recent times several

universities have adopted new strategies for medical education, such as the implementation of integrated curricula that prioritise problem-based learning approaches. However, it is important to note that while some universities have embraced these progressive approaches, others have continued to adhere to the traditional model which means that there is uneven training of health practitioners across the country (Telmesani et al., 2011).

To address the shortage of Saudi-born students pursuing healthcare careers, the Saudi government has implemented various strategies. One such solution involves engaging the private sector in funding and establishing medical schools, increasing the capacity of health colleges, offering scholarships for health professionals, establishing training centres, and providing training in hospitals (Jannadi et al., 2008). An example of government initiatives aimed at expanding the Saudi health workforce is the collaborative effort between the Ministry of Education and the MoH through the King Abdullah international scholarship program, which prioritises healthcare workers (Almalki et al., 2011).

According to recent statistics, the total number of students enrolled in medicine and health universities reached 84,172 individuals in the 2018-2019 academic year (Ministry of Health, 2018) in contrast to 61,421 in 2014 (Ministry of Health, 2014). This increase shows a positive trend in the growth of students pursuing healthcare majors over the years. Additionally, the MoH has consistently provided ongoing training opportunities for healthcare professionals in all disciplines. The objective of these initiatives is to enhance their efficiency and performance by ensuring they remain up to date with the latest advancements in technology, methodologies, and modern healthcare systems (Ministry of Health, 2018). These efforts aim to equip healthcare professionals with the necessary knowledge and expertise in specialised fields, enabling them to effectively meet evolving

healthcare needs. The training programs encompass a range of initiatives, including fellowship programs, postgraduate studies, quality assurance workshops, and technical skills training courses, such as advanced cardiovascular life support and critical care nursing (Ministry of Health, 2013a). In 2018, the total number of healthcare professionals receiving training amounted to 56,118 (Ministry of Health, 2018). This increased from 43,245 trainees in 2014 (Ministry of Health, 2014). This increase highlights the commitment to enhance healthcare professionals' knowledge and skills. However, these training programs primarily emphasise clinical practice rather than the enhancement of interpersonal skills and communication with patients for improving healthcare practice. Evidence from Saudi Arabia indicates that the integration of interpersonal skills into undergraduate and postgraduate curricula is infrequent (Al-Zahrani et al., 2015). This lack of training may serve as a barrier to patient-provider interaction and, consequently, hinder patient engagement in their care (Al-Zahrani et al., 2015). Therefore, healthcare organisations need to incorporate effective communication awareness and training programs while providing ongoing education to their healthcare providers (Falatah et al., 2022).

In summary, Saudi Arabia has made significant progress in improving its healthcare system; however, there are new and emerging health challenges that need to be addressed. Through the implementation of healthcare reforms, investments in medical education, and efforts to tackle NCDs, the country is actively working towards meeting the changing healthcare demands of its population and ensuring the delivery of healthcare services of the highest quality. Furthermore, the transition towards a patient-centred care approach is essential considering the nature of the challenges faced by the health system and the effectiveness of this approach for addressing them. The Saudi government is actively advancing towards adopting a patient-centred approach, which highlights the importance of research which articulates the preparedness of both the population and healthcare

providers for embracing these changes. It is this topic which will be explored in this thesis.

Project Overview and Aims

The objective of this thesis is to provide evidence which will be useful for the development of policies that govern the implementation of patient-centred care in Saudi Arabia. By examining the perspectives of patients and health practitioners towards PCC via quantitative and qualitative methods and conducting in-depth analysis of these results, this study aims to offer a comprehensive understanding of the current nature of patient-centred practice within the healthcare system of Saudi Arabia. In doing so, the project answers three specific research questions:

1. What is the current form of patient involvement in healthcare practice in Saudi Arabia?
2. How do healthcare providers enable and empower patient involvement in healthcare encounters?
3. What model is most appropriate for improving patient involvement in practice in Saudi Arabia?

Significance of the study

The global interest in PCC has led to an increase in research studies focusing on this area. However, there is a gap in the literature when it comes to understanding the perception of patient involvement in care the Middle East and North African region, including Saudi Arabia, particularly in relation to the perspectives of patients and healthcare providers. This research aims to contribute to the field of patient-centred care by providing a Saudi perspective on the perceptions of both patients and healthcare providers regarding patient involvement in care. By including the perspectives of both parties, a more comprehensive

understanding of the current state of patient involvement can be achieved. The findings of this study will be valuable in several ways. Firstly, they will contribute to the existing knowledge base on patient-centred care, filling a specific gap in the literature regarding Saudi Arabia. Secondly, by exploring the patient experience of involvement in care, the research will provide insights into the actual implementation and effectiveness of patient-centred care practices in the Saudi Arabian healthcare context. The implications of this research extend beyond Saudi Arabia. Other Arab countries with similar cultural and healthcare contexts may also benefit from the outcomes of this study. By shedding light on the perceptions and experiences of patients and healthcare providers, the research may inform and guide efforts to improve patient experience, to implement patient-centred care approaches, and to improve our broader understanding of the cultural context of patient-centred care.

Outline of the thesis

This thesis is structured to include published and submitted articles relating to the empirical data collection, alongside chapters that explore the literature relating to the practice of patient centred care and, finally, discuss the implications of the collective empirical findings in relation to that literature. In doing so this thesis investigates the implementation of patient- centred care by examining the perceptions of diabetic patients and healthcare providers regarding the delivery of PCC in Saudi Arabia. It consists of both published and submitted articles, organised into eight chapters, covering four distinct research studies, as follows.

Chapter One: This present chapter has provided background information about Saudi Arabia, including the demographic and economic status of the country. It also describes the Saudi healthcare system's historical development, the country's changed health burdens and

the current government's efforts to transform the healthcare system to improve health services. This chapter is important for the thesis because it sets up the scene for this program of research and explains the research questions and thesis structure.

Chapter Two: This chapter presents a review of the relevant literature and provides international perspectives on PCC practice, factors that influence the delivery of PCC, and different models proposed by international organisations promoting PCC.

Chapter Three: This chapter describes different methods used to address the thesis aims. It details the research design with a focus on the research paradigm and the significance of employing mixed methods approaches. It describes the development and purpose of the different methods utilised in the thesis. Various types of mixed method designs are explored, and a rationale is presented for utilising mixed methods in the context of this thesis. Furthermore, it highlights the ethical considerations and data collection and analysis processes used.

Chapter Four: This chapter presents a published systematic review of PCC delivery in the Middle East and North African (MENA) region. The aim was to address the structural and cultural barriers hindering the implementation of PCC in the MENA region and to develop an initial culturally sensitive definition of PCC that takes into account the unique circumstances and cultural context of the region. This study has been published in the journal, *BMC Health Services Research*.

Chapters Five and Six: These chapters respectively present the qualitative and quantitative findings, of a mixed-method study exploring patient experiences and preferences towards their involvement in care. The qualitative study in Chapter five has been published in journal, *BMC Health Services Research*.

Chapter Seven: This chapter presents the quantitative results of a study of healthcare providers working in Saudi Arabia that evaluated their understanding and implementation of PCC in Saudi Arabia.

Chapter Eight: This chapter presents a comprehensive overview of the study findings and a discussion of the collective study findings in relation to existing literature. It also provides recommendations for practice changes in relation to the findings, outlines potential avenues for future research, highlight the strengths and limitations of the research, and provides a general conclusion.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

This chapter offers an overview of the existing international research on PCC, aiming to enhance our understanding of its implementation and practice. The structure of this chapter is as follows. First, it begins with a concise introduction to the concept of patient-centred care. Next, it explores the evolution and emergence of the movement towards patient-centred models of care, providing insights into the factors that have contributed to its prominence. This section describes several examples of the practice of patient-centred care across different countries, offering an overview of the various models that have been developed and implemented globally. The discussion of these examples explores the factors that influence the practice of PCC and the impact of cultural norms on PCC. Together this discussion provides an understanding of the existing frameworks in place to understand, implement and practice PCC internationally as a background to considering the current practices in the Middle East and North Africa region, and Saudi Arabia specifically, which will be discussed in the thesis results chapters. As literature from the developing MENA region (the focus of my program of research) is scarce, this review mostly draws on literature from non-MENA countries.

What Is Patient-Centred Care?

There is currently no universally agreed-upon global definition of PCC (Australian Commission on Safety Quality in Health Care, 2011; International Alliance of Patients'

Organizations, 2007). However, while multiple definitions of PCC exist, they share fundamental concepts. The concept of PCC has been defined by the United States-based Institute of Medicine as the provision of care that respects and acknowledges the distinct preferences, needs, and values of every individual patient, with the patient's values serving as the primary influence in all clinical decision-making processes (Institute of Medicine, 2001). It is generally understood that PCC centres care around relational attributes such as compassion, empathy, and attentiveness to address the specific needs, values, and expressed preferences of each patient (Institute of Medicine, 2001). Gerteis et al. (1993), postulated six dimensions of PCC: (1) respecting patients' values, preferences, and expressed needs; (2) coordinating and integrating care; (3) providing information, communication, and education; (4) ensuring physical comfort; (5) offering emotional support to alleviate fear and anxiety; and (6) involving family and friends. In 2004, the Picker Institute embraced these dimensions, and they have been employed since to assess the implementation of patient- centred care in the US and Europe (Zill et al., 2015). Patient-centred care is also associated with the terms; person-centred, family-centred care, consumer centred care, relationship-centred care and shared decision-making. These different terms are briefly described as follows:

Person-centred Care

The concept of person-centred care is defined as "… an approach to practice established through the formation and fostering of healthful relationships between all care providers, services users and other significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development" (McCormack & McCance, 2016, p. 20). This

approach underscores an holistic perspective on care, where the focus extends beyond a person's condition or symptoms to encompass their preferences, wellbeing, and broader social and cultural context (Harding et al., 2015). In other words, person centred care centres around individuals, considering their specific context, personal history, family dynamics, and individual strengths and vulnerabilities (Håkansson Eklund et al., 2019). The Health Foundation – an independent non-for-profit organisation aiming to promote better health in UK (The Health Foundation, 2023) - has identified four principles to person-centred care including: providing individuals with respect, compassion, and sense of dignity; providing individualised care, support, or treatment; delivering integrated care, support, or treatment; and assisting individuals in identifying nurturing their own strengths and capabilities to empower them to lead independent and satisfying lives (Health Foundation, 2016).

Person-Centred vs. Patient-Centred

While "person-centred" and "patient-centred" are often used interchangeably, Zhao et al. (2016) provide clarification on their distinctions. They highlight key aspects which set patient-centred care apart from person-centred care. Patient-centred care primarily concerns individuals dealing with illness, undergoing treatment, or managing their health, while person-centred care places a broader focus on individuals regardless of their current medical condition (Zhao et al., 2016). In terms of decision-making, person-centred care places the individual at the core, whereas patient-centred care extends the scope to encompass the input of family members. Patient-centred care arguably revolves around the recipient of care, whereas person-centred care takes a more comprehensive view, factoring in the person's context and relationships in their environment (Zhao et al., 2016). Håkansson Eklund et al. (2019) have suggested that patient-centred and person-

centred care exhibit superficial similarities, such as empathy, respect, and engagement. However, they propose that both terms serve different objectives. Person-centred care aims to provide a meaningful life, whereas patient-centred care aims to ensure a functional life (Håkansson Eklund et al., 2019). This distinction provides clarity regarding the differences between these two care models.

People-centred care

The WHO describe people centred care as "an approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that are organised around the comprehensive needs of people rather than individual diseases, and respects social preferences" (World Health Organization, 2016a, p. 2). This approach has a broader perspective than patients and person- centred care by also including the communities that sit around an individual, recognising their important role in support for the individual, and in designing health policy and services (World Health Organization, 2016a). In other words, it ensures the improvement of health and well-being by taking into account the holistic needs and objectives of the community. This approach prioritises public health and values quality of life as an important outcome than quality of care (Goodwin, 2014).

Family-centred care

The concept of family-centred care has been put forth to encompasses the needs of not only the patient but also their familial support network (Kokorelias et al., 2019). The Institute for Patient and Family-Centred Care defines family-centred care as collaborative efforts among patients, families, and health providers, as well as planning, delivering, and evaluating health care, and in education and research (Eichner et al., 2012). "Patient and family-centred care" (PFCC) closely resembles family-centred care in its recognition of family members as a constant presence in a patient's life and its

acknowledgment of the valuable contributions they provide to their child's healthcare journey (Brown et al., 2008). Essentially, this approach represents a holistic approach to patient interests, desires, and encouragement, where the focus is placed on upholding patient values in decision-making and working with patients and families to strengthen treatment (Feinberg, 2014; Millenson et al., 2016).

PFCC emphasises the direct incorporation of patient and family perspectives into the entire healthcare process, which ultimately leads to improved quality and safety of care (Institute for Patient- and Family-Centered Care, 2017). It also recognises patients and their families as essential partners in quality improvement, safety initiatives, healthcare education, research, facility design, and policy development (Institute of Patient and Family Centered Care, 2021). This approach is guided by the four concepts of dignity and respect, information sharing, participation, and collaboration (Conway et al., 2006). The term PFCC has been used in several healthcare settings, including paediatric and maternal hospital wards and community healthcare facilities for adults and the elderly (Park et al., 2018).

Consumer-centred Care

The term consumer-centred care has been used interchangeably with patient-centred care. The use of this term increased during the patient rights movement in the 1960s and was deliberately used with the intent to imply a more active patient role when interacting with healthcare providers (Goldstein & Bowers, 2015).

Relationship-centred Care

The concept of relationship-centred care suggests that the foundation of any healing process is based on interactions between individuals (Wylie & Wagenfeld-Heintz, 2004). This model was founded upon four principles: (1) that relationships in healthcare should

recognise the personhood of all individuals involved, (2) that affect and emotion play a key role in these relationships, (3) that relationships involve back-and-forth interactions, and (4) that the creation and fostering honest relationships in health care is morally responsible (Beach & Inui, 2006). The relationship between patients and providers is central to this model of care.

Shared decision-making

Shared decision-making (SDM) is a key phrase used both separately and as a fundamental element of PCC, concerned with promoting and enabling patients to take an active role in managing their own health (Smith, 2016). It is referred to as "…an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences" (Elwyn et al., 2012; Elwyn et al., 2010). This approach has a strong emphasis on fostering mutual partnerships between patients and healthcare providers, mutual information exchange and communication (Charles et al., 1999; Inzucchi et al., 2012; Montori et al., 2006). Stiggelbout et al. (2015) describe it as a process that encompasses the healthcare provider engaging in the following steps:

- Informing the patient of the impending decision to be made emphasises the significance of the patient's viewpoint on this decision.
- Clarifying available options and their respective advantages and disadvantages.
- Fostering a collaborative discussion about the patient's preferences while offering support.
- Engaging the patient to their desired level in the final decision-making process.

Partnership in care

The partnership-in-care approach, now known as “The Montréal Model” (2010) developed by the University of Montreal through collaboration between patients and health professionals (Dumez & Pomey, 2019), is based on several core principles. These include empowering patients to make informed decisions, recognising the value of experiential knowledge gained from living with illness, developing skills throughout the care process, considering oneself as an active participant in care, and focusing on achieving overall life goals rather than solely on curative objectives (Dumez & Pomey, 2019). In this approach, patients can be partners in various ways (Karazivan et al., 2015; Pomey et al., 2019; Pomey et al., 2015). This includes engaging in dialogue and exchanging their perspectives on illness and its effects on their daily lives with a diverse team of healthcare professionals. Patients can also contribute their personal experiences to help other individuals manage their condition (Pomey et al., 2019; Pomey et al., 2015) or contribute to the education of future healthcare providers by participating in workshops, providing monitoring, or offering training. Patients can also provide valuable insights by allowing future healthcare professionals to shadow them during their care or serve as "Experience Collectors" by sharing their personal experiences with researchers. They can also take part in shaping and overseeingresearch procedures through involvement in formulating research inquiries, drafting protocols, recruiting participants, analysing data, and sharing findings (Pomey et al., 2019). Patient involvement in research is viewed as important because it enhances research quality and, consequently, improves the standard of patient care (Pomey et al., 2019).

Summary of different terms

These terms collectively emphasise the growing recognition of the significance of individualised, compassionate, and collaborative healthcare, with each term having a unique focus within the realm of care delivery. Hughes et al. (2008) conducted a review to

investigate the rationale for employing various forms of care centred around the client, family, patient, person, and relationships. The study revealed that, on a conceptual level, there were no significant thematic differences among these different forms of centred care (Hughes et al., 2008). However, it concluded that different types of centred care were necessary in distinct contexts.

Given the description of these terms, this thesis has adopted 'patient-centred care' for use in the thesis. This is because it specifically explores into the experiences of individuals dealing with illness and seeking medical treatment (Zhao et al., 2016). Furthermore, the recent focus of the Saudi government on enhancing healthcare through the adoption of PCC has also influenced this choice (Ahmad et al., 2020).

Benefits of adopting a Patient-centred Care approach

Patient-centred care has gained global recognition as one of the essential dimensions of healthcare quality (Institute of Medicine, 2001). It is a widely embraced concept in healthcare delivery that has demonstrated tangible benefits in various studies conducted in different countries such as the Netherlands (Kuipers et al., 2019), the United States of America (US) (Bertakis & Azari, 2011; Deen et al., 2011; Roumie et al., 2011; Stone, 2008; Vanderboom et al., 2014), Canada (Temple-Oberle et al., 2014), and Germany (Loh et al., 2007). These studies have shown that the practice of PCC is associated with positive outcomes for patients. PCC has been suggested to lead to increased patient satisfaction (Kuipers et al., 2019; Loh et al., 2007; Temple-Oberle et al., 2014), improved physical and social well-being (Kuipers et al., 2019), reduced hospital utilisation (e.g., number of visits, hospitalisation, and laboratory and diagnostic tests) (Bertakis & Azari, 2011; Stone, 2008), a decrease in total financial costs (Bertakis & Azari, 2011), enhanced adherence to medication (Loh et al., 2007; Roumie et al., 2011) and improved patient care (Vanderboom

et al., 2014). An example of these findings is an observational cohort study involving 39 family physicians practising in London, Ontario, Canada, and the surrounding area and 315 of their patients (Stewart et al., 2000). The study aimed to assess the association between patient-centred communication during primary care visits and subsequent health outcomes and medical care utilisation. The findings revealed that there is indeed an association between PCC and improved health status, including reduced discomfort, decreased concern, and better mental health. Additionally, patient-centred practice was linked to increased efficiency of care, such as a reduction in the number of diagnostic tests and referrals (Stewart et al., 2000). These findings highlight the significant impact and value of implementing PCC in healthcare settings. Similarly, a separate 2016 study carried out in the US aimed to assess the connection between PCC, self-care for diabetes, glycaemic control, and the quality of life among adults with type 2 diabetes. The results of the study demonstrated a notable correlation between patient-centred care and both the quality of life and self-care behaviours of the participants (Williams et al., 2016). These findings were further supported by a review conducted by Olesen et al. (2020), which concluded that patient-centred diabetes self-management education and support have a substantial influence on diabetes-related outcomes in individuals living with type 2 diabetes.

In summary, patient-centred care benefits patients by promoting patient satisfaction, better health outcomes, and cost-effective care. It emphasises the importance of treating each patient as an individual with unique needs and preferences, ultimately leading to a more personalised and effective healthcare experience.

Moving to Patient-Centre Care

Patients' roles in the health care system have evolved over the years in developed countries as the health system model has changed from a paternalistic to a patient and family-centred

care model and, more recently, to a partnership in care such as that represented by shared decision-making, discussed above. Paternalism may be described as an action taken by one person in the best interests of another, without their consent (Thomasma, 1983). In other words, a paternalist model of healthcare views the healthcare provider as a figure who decides what the best interests of the patient are and acts on this without genuinely consulting the patient (Qidwai, 2003). Consequently, under this approach, healthcare providers make decisions while patients rarely contribute to the decision-making process and it is therefore a one-way relationship (Dumez & Pomey, 2019; Pomey et al., 2015). For instance, in the US, family members of young patients were not considered a part of the healthcare team because the healthcare team were considered to be experts who would notify the families of what to do, and families were considered to be non-experts (Wells, 2011).

According to Igel and Lerner (2016) the transition towards patient autonomy and the development of family-centred patient care resulted from a series of medical scandals, including the disclosure of the Nazi Medical experiments during World War II and the United States Public Health Service's Tuskegee syphilis study. Initiated in 1932 in Macon County, Alabama, in the US. This experiment targeted 800 African American males, 400 with late or latent untreated syphilis and 200 without syphilis infection as a control sample. The initial study timeline was 8 to 9 months; however, it extended to 40 years and even after finding the efficacy of penicillin and having it approved for syphilis treatment in 1950, the study subjects did not receive the treatment. When recruited into the study, the study subjects were dealing with discrimination and had many barriers to accessing healthcare (Brandt, 1978; Paul & Brookes, 2015), and participation in this study was an opportunity to receive free meals, medical examinations, and funeral insurance (Centers for Disease Control and Prevention, 2022). This meant that the people in the study were in effect

coerced into the study. A patient-centred approach would not have treated these people in this way, instead valuing their full consent and views on the study.

Another instance of unethical experiments are those undertaken by Nazi doctors and scientists, one of which occurred in 1942 at the Ravensbrück women's concentration camp (Frankenburg, 2017). This experiment involved deliberate mutilation and infections to examine the effects of sulphonamide antibiotics. It entailed the removal of bone and muscle from women, often without the use of anaesthetic agents, for the purpose of studying the regeneration of bone, muscle, and nerves (Frankenburg, 2017). One of the objectives of these experiments was to explore the feasibility of replacing limbs and other body parts for injured German soldiers (Frankenburg, 2017). These examples highlight the imperative behind the shift towards ethical and patient-centred healthcare, and more broadly respecting the dignity and autonomy of individuals in medical practice.

However, the shift from paternalistic to patient and family-centred care was not only motivated by unethical experiments. It was also due to the limitations of the paternalistic approach in meeting the health demands of the population. According to Dumez and Pomey (2019), these limitations became apparent when dealing with individuals with addiction or mental health issues who required more compassionate care. The authors added that the growing prevalence of chronic illnesses had exposed the inadequacy of prioritising disease treatment over patient care and acute curative care over the integration of primary care and long-term care (Dumez & Pomey, 2019). In light of these limitations, a more holistic approach to healthcare was deemed necessary, where the patients' needs and values are prioritised over the disease (Dumez & Pomey, 2019).

In 1969, the concept of patient-centred medicine was introduced (Balint, 1969; Håkansson Eklund et al., 2019) as a departure from traditional healthcare approaches, which were

predominantly disease-focused or physician-oriented (Entwistle & Watt, 2013). Patient-centred medicine marked a significant shift in medical thinking (Balint, 1969; HåkanssonEklund et al., 2019), emphasising the importance of incorporating patient needs and preferences into the care delivery process, shifting from "care to patients" to "care for patients"(Clavel et al., 2021). The patient-centred care approach is grounded in respect and responsiveness, with a focus on addressing the needs, values, instructions, physical comfort, and emotional well-being of the patient, as well as effective communication with patients and their significant others. It adopts a biopsychosocial perspective, emphasising the therapeutic relationship, patient empowerment, and the recognition of each patient as an individual (Jasemi et al., 2017). Evidence has shown that adopting a PCC can lead to better patient outcomes, increased patient satisfaction and self-management, and improved quality of life (Park et al., 2018; Rathert et al., 2013).

In summary, the historical evolution of patient role in the healthcare, moving from the paternalistic approach to patient centred approach one, was driven by several factors. These included unethical experiments and a growing recognition of the need to an approach that is more patient centred. This transformation signifies a shift toward respecting individual autonomy and adopting a holistic approach to cater to the diverse needs of patients.

International Models of PCC

While there is growing recognition of the significance of implementing patient-centred care, healthcare organisations may face challenges in both implementing and sustaining PCC in practice (Australian Commission on Safety Quality in Health Care, 2011). Consequently, several organisations and models have advocated for and developed guidelines to uphold the philosophy of patient-centred care. The following section provides a brief description of these organisations and models.

The World Health Organization

The WHO is a key proponent of PCC, and with members including most nations worldwide, their support for PCC has considerable reach. In 2007, the WHO introduced a policy framework to guide countries and health partners towards PCC. They advocated that implementing PCC can be achieved through promoting a culture of patient involvement. This culture would involve patients in care-related decisions and demonstrate respect and responsiveness to patient's needs on the part of providers. This change must be delivered in a context where services are affordable, accessible, and safe and within supportive healthcare environments. These must be based on the involvement of patient stakeholders in planning health services, developing policies and providing feedback for quality improvement (World Health Organization, 2007).

Picker Institute

PCC has also been promoted and developed by independent international bodies such as the Picker Institute. The Picker Institute is a non-profit organisation based in the US (Frampton et al., 2008). It was established in 1994 and attempted to set standards and processes for PCC by implementing nationwide surveys and databanks focused on patient-centred care, which healthcare workers could utilise to promote health services from a patient's perspective (Frampton et al., 2008). Their goal was to promote a more humane model of care (Gerteis et al., 1993). The institute bases its definition of the dimensions of integrated care on a study that they undertook which aimed to explore patients' perceptions of their needs and concerns to foster a humane model of care. The study used focus groups with patients and their family members, a literature review, and consultation with healthcare providers to develop the definition (Gerteis et al., 1993). Through this, the Picker Institute articulated the dimensions of patient-centred care. These dimensions are: quick access to

healthcare; receiving efficient and reliable treatment from trusted experts; continuity of care and seamless transitions; engagement and assistance for family members and caregivers; transparent communication and encouragement for self-care; involvement in decision-making and respect for patient preferences; emotional support, compassion, and dignity; attentiveness to physical and environmental requirements (Picker Institute, 2021). This framework established a clear definition of the viewpoint from the patient's standpoint, which was subsequently used for the development of the Picker surveys used to assess the patient's healthcare experience (Australian Commission on Safety Quality in Health Care, 2011). For example, the Picker Patient Experience Questionnaire (PPE-15) was developed to measure patient experience across various aspects of care. It consists of fifteen questions that span the dimensions of the patient-centred care (Jenkinson, 2002; Jenkinson et al., 2003; Leonardsen et al., 2017).

Planetree

Another international organisation promoting PCC is Planetree. Planetree is a not-for-profit organisation instituted by Angelica Thieriot in the late 1970s in the US with the intent of changing health organisation culture and improving patient experiences (APB Speakers; Frampton, 2005; Frampton et al., 2008; Stone, 2008). Based on a collaboration between patients, families, and healthcare providers via focus groups, the organisation identified nine elements of patient-centred care which are (Frampton, 2009; Frampton et al., 2003; Stone, 2008):

- Human interaction.
- Building partnerships with family members and friends.
- Access to information and patient education
- Creating healing environments through thoughtful architectural and design.
- Food and nutrition.

- Spirituality.
- Human touch.
- Integrating complementary and alternative practices into standard care.
- Healing arts.

The model is currently recognised and used in diverse health organisations around the globe (Charmel & Frampton, 2008; Frampton et al., 2008; Stone, 2008). Like the Picker Institute, Planetree collaborates with healthcare organisations worldwide, offering a framework for achieving excellence in person-centred care. Many healthcare organisations around the globe have become Planetree Person Centred Certified organisations in countries including Saudi Arabia, Australia, Canada, United States of America and France (Planetree, 2021). To date, several healthcare organisations in Saudi Arabia have received gold certification from the Planetree: for example, Johns Hopkins Aramco Healthcare, Saudi German Hospital, and Sultan bin Abdulaziz Humanitarian City. These international models and organisations are pivotal in advancing patient-centred care, advocating for patient involvement, and enhancing the overall healthcare experience for individuals and their families. These collective efforts have significantly contributed to the global adoption of PCC as a fundamental healthcare standard, empowering patients and elevating the quality of their healthcare experiences worldwide.

Centre of Excellence for Partnership with Patients and the Public

The Centre of Excellence on Partnership with Patients and the Public (CEPPP) was established in May 2016 through a partnership between the Faculty of Medicine and the research centre of the Centre hospitalier de l'Université de Montréal (Institute For Patient and Family Centered Care, 2024). The centre aims to establish patient, caregiver, and public partnerships as a fundamental aspect of healthcare improvement (CEPPP, 2024a). It

manages a platform that fosters patient engagement (CEPPP, 2024b) and, therefore, plays a role in developing the Montreal model (Pomey et al., 2019). The CEPPP has created a diverse set of tools to help evaluate patient and public engagement efforts in healthcare and health research (CEPPP, 2024c). The surveys conducted for patients, caregivers, and researchers have a common aim: to understand the real experiences of researchers who collaborate with patients and caregivers as part of the research team. Similarly, the surveys for researchers also seek to comprehend their experiences when working with patients and/or caregivers (CEPPP, 2024b).

Factors Which Influence the Practice of PCC

Patient preferences for involvement

A plethora of studies have examined patients' preferences for their involvement in care and have found that patients varied regarding their perception of, and preferences for, their involvement. For example, Arora and McHorney (2000) reported that the majority of patients with chronic illness preferred to leave the decision-making to health care providers and therefore take a "passive role", in contrast to other studies, which reported that patients preferred to participate in decision-making with the health care providers, described as an "active role" (Hwang et al., 2014; Murray et al., 2007; Nota et al., 2016; Peek et al., 2008; Ryan & Sysko, 2007). This variation in preferences and experiences of patient involvement in care depends on several factors that related to patients and health providers (Sainio et al., 2001). Quantitative studies have reported patients' characteristics as factors influencing their involvement in care. For example, young patients, females and those with a high level of education have been found to be more likely to prefer to be actively involved in care, while patients of older age, males and those with a low level of education have been found to be more likely to prefer to be less involved in care (Arora & McHorney, 2000; Benbassat

et al., 1998; Flynn et al., 2006; Murray et al., 2007; Ryan & Sysko, 2007). In a Chinese study conducted to investigate patient perceptions of PCC, it was reported that patients with low education levels were found to be inadequately prepared for their consultations and exhibited hesitancy when it came to participating and communicating with healthcare providers (Ting et al., 2016). Patient preferences for their involvement might also change as they grow older and the stage of their illness progresses (Levinson et al., 2005). According to Brody (1980), there are several reasons why patients may prefer not to be involved in their care. These reasons include their concern about being involved in critical decisions with life-or-death implications, patients having trust in their healthcare provider's knowledge and authority, and patients not wanting to bear the responsibility for the outcomes of decisions. For example, in a study conducted in Saudi Arabia examining patients' perceptions of their participation during interactions with healthcare providers, patients receiving care in cardiology and cardiac surgery departments had lower levels of involvement due to the need for critical health-related decisions, resulting in healthcare providers adopting a paternalistic model (Aljaffary et al., 2020).

In summary, this discussion highlights the variability in patients' preferences for involvement in their healthcare decision-making and outlines the factors that contribute to these preferences. It emphasises the role of patient characteristics and educational background in shaping preferences and highlights reasons why some patients may decide for a less active role in their care. This information underscores the importance of recognising individual patient preferences and tailoring healthcare approaches accordingly.

Provider knowledge and preferences regarding PCC

While healthcare providers generally acknowledge the significance of patient involvement in their own care, there is a notable divergence in their understandings and interpretations of

the concept of PCC. Recent research has cast a spotlight on the perceptions and interpretations of shared decision-making and PCC within the realm of healthcare decision-making among healthcare providers. For example, Abubaker-Sharif et al. (2022) conducted research with primary care physicians concerning their perception of shared decision-making in lung cancer screening. Physicians were aware of SDM and believed that utilising SDM could be beneficial in recognising concerns that are significant to patients and might impact their willingness to engage in cancer screening. The prevailing attitude observed was associated with a paternalistic model of shared decision-making, where healthcare providers take the lead in decision-making. However, there were also those who preferred a neutral stance throughout the deliberation process, allowing patients to have more autonomy. Additionally, some participants expressed the view that decision-making should be an informed choice process, emphasising the importance of providing patients with all the necessary information to allow patients to make their own decisions (Frerichs et al., 2016).

Furthermore, healthcare providers acknowledged that SDM may not always be the suitable approach in the decision-making process. The study showed that healthcare providers infrequently describe SDM in a manner consistent with its definition in the international literature. The same point was demonstrated in Fix et al. (2018) qualitative study of 107 employees in four veteran health administration medical centres where the understanding of PCC among employees, particularly those in leadership positions, did not completely align with the PCC framework described in the literature. However, it was found that the employees' broad perspective might be influenced by the organisation's vision which may hinder the implementation of essential components of PCC. According to Fix et al. (2018), vague conceptualisations of PCC signify a desire to be patient-centred, but without a clearer definition, they fail to provide adequate and practical guidance for effectively

implementing cultural transformation. This misconception of SDM impedes its effective implementation (Hoffmann et al., 2014). In a study by Hofstede et al. (2013), which included 40 semi- structured interviews with healthcare providers involved in sciatica care and three focus groups with patients, it was noted that a significant number of healthcare providers found the concept of SDM unclear.

Barriers and facilitators to PCC

International studies conducted outside of the MENA region, in Europe, Asia, North America, and Australia, have provided valuable insights into the barriers and facilitators to the implementation of patient-centred care. This extensive body of research underscores the universal significance of PCC while revealing the intricate web of challenges and facilitators encountered at various levels within the healthcare system.

Effective patient-centred care is a critical component of delivering high-quality healthcare (Institute of Medicine, 2001). However, numerous barriers at the patient level can impede the successful implementation of PCC, impacting the patient's experience and outcomes. One major barrier is inadequate health literacy (Abubaker-Sharif et al., 2022; Peek et al., 2009). Many patients struggle to understand the information shared by healthcare providers and, as a result, become less active in their care (Edwards et al., 2012; Erlen, 2004). Patients also often possess limited knowledge and information about their condition and treatment options (Charles et al., 2004; Hofstede et al., 2013), and they may receive incomplete or inaccurate information, making it challenging for them to make informed decisions about their care (Charles et al., 2004; Hofstede et al., 2013). Therefore, some patients may have negative attitudes towards participating in their care (Charles et al., 2004; Du et al., 2020; Hofstede et al., 2013; Wubben et al., 2021), leading to reluctance to engage in decision-making or interact with healthcare providers. This may also be due to

fear, anxiety, or previous negative experiences (Belcher et al., 2006). One potential approach to addressing these barriers is through improved patient education. Charles et al. (2004) stated that patients' knowledge about their disease and treatment options is considered crucial in the context of shared decision-making. Patients who are well-informed, possess cognitive ability, and express a desire for involvement contribute significantly to their participation in decision-making (Frerichs et al., 2016). Patients may lack a clear understanding of the roles of different healthcare providers, hindering effective communication and collaboration (Chong et al., 2013; Kim & Kim, 2023; Younas et al., 2016).

Trusting healthcare providers is essential for effective PCC. When patients do not trust their healthcare team (Du et al., 2020), they might become less motivated to participate in decision-making. This lack of trust patients have toward healthcare providers can negatively impact their well-being by discouraging the use of preventive services and reducing adherence to clinical advice (Li & Khan, 2022). Having trust in the expertise and interpersonal abilities of healthcare providers serve as a facilitator to an effective patient provider relationship (Charles et al., 2004; Peek et al., 2009). Trust is linked to many aspects positive for healthcare including, following treatment advice, maintaining consistency with the same physician, refraining from seeking additional opinions, being more inclined to suggest the physician to others, experiencing fewer disagreements with the physician, perceiving higher care effectiveness, and self-reported health improvement (Hall et al., 2001). Patients often experience a range of emotions related to their illness, including worry, denial, and fear, which can act as a barrier to their active participation in decision-making and effectively communicating their needs (Abubaker-Sharif et al., 2022; Peek et al., 2009). Interestingly, family involvement had also been perceived as a barrier by healthcare providers, possibly because they are concerned that family members could

interfere with the patient's autonomy or disrupt the care process (Paiva et al., 2019). Nonetheless, its crucial to recognise that family support is a substantial facilitator acknowledged by both patients and healthcare providers (Chong et al., 2013; Paiva et al., 2019; Peek et al., 2009). In many cases, the involvement of family members can provide invaluable emotional and financial support, playing a significant role in patient care (Babaei & Abolhasani, 2020).

Effective communication is at the heart of PCC. Healthcare providers who utilise clear language and view patients as partners in their care are recognised as enablers of PCC (Paiva et al., 2019). On the other hand, healthcare providers lacking adequate communication skills may struggle to convey complex medical information in an understandable manner, resulting in misunderstandings (Frerichs et al., 2016; Hofstede et al., 2013; Kim & Kim, 2023; Peek et al., 2009). Patients expect to receive clear and comprehensive information about their condition during consultation (Raja et al., 2015). When healthcare providers do not provide sufficient information or explanation, patients may feel uninformed and disengaged from their care, further hindering patient-provider interactions (Jenerette & Mayer, 2016). Healthcare providers with their medical knowledge, technical skills, and interpersonal abilities directly impact patients' ability to engage in their care effectively (Peek et al., 2009). Providers who exhibit proficiency in these areas can create an environment that encourages patient participation and collaboration (Duffy et al., 2004; Rider & Keefer, 2006; Travaline et al., 2005).

Healthcare provider attitudes towards patient involvement are also considered a barrier to PCC, with some healthcare providers holding negative attitudes towards patient involvement (Hofstede et al., 2013; Moore et al., 2017) or having limited awareness of PCC (Kim & Kim, 2023). This mindset can be linked to the historical paternalistic model of

healthcare where the provider makes decisions for the patient rather than collaboratively involving the patient in decision-making (Frerichs et al., 2016). Some healthcare providers may tend to prioritise care tasks or disease centred care and preform their responsibilities mechanically without emotional involvement or recognising the patient as a unique individual (Kim & Kim, 2023). Others may hold the belief that patients lack the capacity to make informed decisions and do not view patient involvement in decision-making as necessarily leading to improved treatment outcomes (Liang et al., 2022). Therefore, it's important for healthcare providers to be aware of how their communication approach, whether it's task-oriented, process-focused, or aimed at addressing the needs of patients and their caregivers, can influence the practice of PCC (Kwame & Petrucka, 2021).

The lack of respect for patients' preferences, values, and autonomy can hinder the practice of PCC (Kim & Kim, 2023; Paiva et al., 2019). It is essential for healthcare providers to recognise that patients have valuable knowledge about their own experiences with illnesses. Thus, healthcare providers should embrace and encourage this expertise by involving patients as partners in their healthcare team (Karazivan et al., 2015). Moreover, an effective PCC often requires collaboration among healthcare professionals from different disciplines. Inadequate teamwork and collaboration can lead to fragmented and suboptimal care (Chong et al., 2013; Dobscha et al., 2016; Hofstede et al., 2013). In healthcare settings with multiple disciplines, there can be mistrust among healthcare providers from different disciplines (Hofstede et al., 2013). For example, a review examining the experiences and perceptions of integrated dementia care revealed issues related to trust among healthcare providers (Smith et al., 2021). This lack of trust can be attributed to several factors, including perceptions of poor collaboration, challenges in engaging with care professionals, misunderstandings about the roles and expertise of healthcare professionals, inadequate understanding, perceived poor attitudes from specialists, time constraints for general

practitioners, and reluctance to consult psychiatrists. This distrust hampers effective knowledge exchange and care integration and this, in turn, can impact on how patient-centred care can be (Smith et al., 2021).

The organisational or system level also plays a crucial role in shaping the practice of PCC. Barriers at this level can have a profound impact on healthcare delivery and the ability of healthcare providers to provide PCC. Studies conducted in Western countries have identified a lack of time as a major challenge to implementing PCC (Charles et al., 2004; Chung et al., 2019; Frerichs et al., 2016; Hofstede et al., 2013; Kim & Kim, 2023; Kwame & Petrucka, 2021; Moore et al., 2017; Paiva et al., 2019; Wubben et al., 2021; Younas et al., 2016), which can be attributed to the high workload and staff shortage that contribute to the limited time available (Kim & Kim, 2023). According to a study of nurses by Loghmani et al. (2014), the shortage of staff and heavy workloads can negatively impact nurses' ability to engage with patients. Similarly, in Iran, a study conducted to investigate the attitudes and experiences of nurses regarding the obstacles in achieving patient- centred in critical care settings reported that many nurses identified insufficient personnel, lack of time, and heavy workload as essential barriers to implementing PCC (Esmaeili et al., 2014).

The lack of education and training on PCC principles and practices can hinder healthcare providers' ability to effectively implement PCC (Kim & Kim, 2023). Many healthcare professionals may not have undergone formal PCC training, which can impact the practical application of PCC. Evidence shows that inadequate training and limited knowledge of PCC by healthcare providers can lead to an ineffective implementation of PCC (Kuipers et al., 2021; Sultan et al., 2018). This deficiency could be attributed to certain educational institutions not adequately incorporating PCC concepts into their curricula (Kim & Kim, 2023). This can also be attributed to current medical education

emphasising a biomedical model which focuses narrowly on disease identification and management and does not involve patients and healthcare providers in its development (Santana et al., 2018). This education gap results in healthcare providers entering the workforce without a clear understanding of the importance of PCC or the requisite skills for its effective implementation.

Patient expectations of care

'Patient expectations', in the context of healthcare, refers to the anticipation that certain events are likely to occur either during or as a consequence of medical treatment (Uhlmann et al., 1984). It is crucial that health practitioners comprehend the patient's expectations of care so that treatment can be adapted to those expectations, and expectations moderated where necessary (Kravitz, 1996). There is strong evidence that fulfilling the expectations of patients is linked to increased levels of patient satisfaction (Dawn & Lee, 2004). Failure to meet patient expectations may result in patients' non-compliance. They may not directly voice their complaints to the healthcare provider but rather decide to discontinue the treatment (Farooqi, 2005; Hoy, 2008; Lateef, 2011).

Several studies have explored patient expectations of care. A study conducted in Iran in 2010, aimed to identify the most important expectations that hospitalised and ambulatory patients (N=400) have from their physicians. The findings indicated that the patients' foremost expectations revolved around the physicians' competency, courtesy, and consultation with other healthcare providers when needed (Dormohammadi et al., 2010). Similarly, a 2020 study was conducted in Australia to explore how patients express and conceptualise their expectations of healthcare across a range of clinical contexts and conditions. This study found that some of the expectations of healthcare providers revolve around the intrinsic qualities of healthcare providers such as professionalism, while others

pertain to what patients anticipate from healthcare providers in terms of care and assistance (El-Haddad et al., 2020). Lateef (2011) identified several common expectations that patients have, which encompasses: 1) to be actively listened to; 2) to receive clear explanations and instructions regarding their medical condition; 3) to be cared for by healthcare staff who exhibit compassion, concern, and empathy; and 4) to be treated by healthcare professionals who demonstrate professionalism in their interactions and medical practices. A literature review focusing on the communicative behaviours desired by primary care patients from their physicians revealed that most patient expectations were associated with building and fostering a strong patient-provider relationship (Deledda et al., 2013). These expectations were primarily concerned with the functional aspects of the physician-patient relationship including being friendly, and treating patients with respect as unique individuals, and not being judgmental (Deledda et al., 2013).

Understanding and meeting these diverse expectations are crucial for delivering patient-centred care, as it can significantly contribute to improving patient satisfaction and enhancing healthcare outcomes (El-Haddad et al., 2020). Meeting these expectations is, therefore, not just a matter of fulfilling a checklist; it's essential for delivering patient-centred care. Doing so not only enhances patient satisfaction but also plays a pivotal role in achieving improved healthcare outcomes. In the pursuit of patient-centred care, understanding and fulfilling these patient expectations are central pillars of success.

Cultural norms and patient-centred care

Building partnerships between patient and provider is a part of the model of PCC (Matthias et al., 2010; Mead & Bower, 2000; Tait, 2008). This relationship is built on a fiduciary commitment, with healthcare providers assuming specific responsibilities (Chipidza et al., 2015). These responsibilities include honouring the patient's autonomy, safeguarding

confidentiality, discussing treatment choices, seeking informed consent, delivering the best possible care, and promising not to abandon the patient without allowing sufficient time to find a new doctor (Chipidza et al., 2015). It is also important to recognise that culture plays a significant role in this relationship (Flores, 2000; Fredericks et al., 2006). Patients' views on health and illness are closely tied to their cultural beliefs (Matusitz & Spear, 2015). This is especially significant for understanding the health needs of migrant patients who may maintain their cultural medical views even after relocating to Western countries (Awasom, 2021). The importance of cultural context suggests that Western notions of PCC will likely be unsuccessful in other countries due to cultural differences in healthcare systems. This was pointed out in a study conducted in Saudi Arabia that examined the perspectives of paediatric nurses on family-centred care and found that nurses recognise the Western concepts of family-centred care (Alabdulaziz et al., 2017). However, the implementation of family- centred care in accordance with Western values may not be suitable or effective in Saudi Arabia, where both nurses and families have a non-Western cultural background. The authors recommended modifying and further developing the Western family-centred care model to fit Saudi and Middle Eastern cultures better. Moreover, healthcare providers must be aware and respectful of their patient's cultural backgrounds. Neglecting to do so could have significant clinical ramifications such as non-adherence and lack of continuity of care (Flores, 2000). To achieve effective culturally responsive care, it is crucial for healthcare providers to communicate in a culturally competent manner. This involves being aware of healthcare inequalities that impact particular populations and acknowledging that socio-cultural factors can significantly affect health beliefs and actions. Healthcare providers should also have the skills needed to effectively understand and provide support that addresses these factors (Brown et al., 2016; Taylor & Lurie, 2004).

The significance of the patient-provider relationship cannot be overstated, as it plays a

pivotal role in yielding positive outcomes resulting from healthcare decisions (Mead & Bower, 2000). These outcomes encompass enhanced patient adherence to treatment, heightened health literacy, and the promotion of continuous care (Gimenes et al., 2009; Kamimura et al., 2020). However, this relationship between individuals and the experiences that arise from it are not always perfect (Chipidza et al., 2015). While every patient establishes a distinct connection with their provider, there are broader social factors at play that shape this interaction, including professional dominance (Freund et al., 2003). Freund et al. (2003) point out that the professionalisation of medicine creates a social distance between patients and healthcare providers, where the provider is perceived as the knowledgeable expert, while the patient assumes the relatively passive position of a recipient of professional services. This social distance is evident in studies conducted in Middle Eastern countries like Pakistan and Saudi Arabia, which highlight the authoritative role of healthcare providers in the provision of care (Aslam et al., 2005; Baig et al., 2020; Banaser et al., 2017). This observation was also noted in a systematic review of studies published between 1990 and 2020 (Vakil et al., 2023). The review aimed to investigate the PCC experiences of first-generation South Asian migrants living with chronic illnesses in high-income Western countries. The findings of the review indicated that the patients displayed passive acceptance and a reliance on their doctors for care. This was largely attributed to their belief that they, as patients, had limited control over their condition and that their doctors were the best qualified to provide care (Vakil et al., 2023).

Furthermore, within the context of patient-provider relationships, three cultural values emerge as significant. These values were identified by Hofstede et al. (2010) and include power distance, individualism, and collectivism. *Power distance* is defined as "the extent to which the less powerful members of institutions and organisations within a country expect and accept that power is distributed unequally" (Hofstede et al., 2010, p. 61). In essence,

this concept reflects the extent to which individuals in societies or organisations are comfortable with hierarchical power structures. Societies or organisations characterised by high power distance exhibit a greater acceptance of unequal power distribution, while those with low power distance tend to anticipate a more egalitarian distribution of power and decision- making authority.

The concept of power distance becomes particularly relevant in the context of patient-provider interactions. Patients who seek to have a more active role in decision-making often face challenges due to the existence of a "power distance." This power distance is created by various factors, such as the physician's authoritative expertise, elevated social status, control over medical resources, and reluctance to share power (Ryan & Sysko, 2007). As a result, the influence of power distance on the patient-provider relationship holds significant implications for the dynamics of healthcare, particularly in cultures characterised by varying degrees of power distance.

The literature clearly demonstrates the impact of power distance on the healthcare provider-patient relationship. For instance, in Australia, a study exploring perceptions of patient-provider communication and ascertained unmet educational needs and preferences (Ivynian et al., 2020), the study revealed that patients perceived doctors as unresponsive to open discussion, thus hindering effective communication. This perception of healthcare providers' failure to encourage open discussions during consultations underscores the impact of prevalent of prevalent social and cultural norms of subordination to medical professionals (Ivynian et al., 2020). Another Australian study examining factors shaping the decision- making process in providing care for patients facing advanced illness, found that patients did not perceive themselves as active participants in decision-making (Lee et al., 2009). This study found that some healthcare providers did not make the effort to establish a

relationship with patients, which led patients to feel detached from the healthcare provider. Moreover, these healthcare providers were perceived as distant, lacking empathy, and more focused on the disease, rather than the individual as a unique person (Lee et al., 2009). The healthcare provider domination of the dialogue was also shown in a qualitative study within an outpatient department of a cancer hospital in China (Tu et al., 2019). The study revealed distinct patterns in the communication process, observing a prevalence of structured conversations, with doctors largely dominating the discourse and a notable emphasis on technology during interactions. These characteristics indicate a significant power imbalance between Chinese doctors and patients at the individual level (Tu et al., 2019) which, as with the Australian studies, impacts the context in which PCC can take place.

In an effort to better understand the nature of power dynamics within the patient-provider relationship, a Canadian study aimed to explore how experienced physicians perceive power and its distribution within the patient encounter (Nimmon & Stenfors-Hayes, 2016). The study found that there was variation among physicians in how they perceived and understood power dynamics in the physician-patient relationship. Some physicians held the view that their medical training and qualifications gave them a position of power during the interaction. Other physicians held the belief that, due to the trust patients place in their expertise and authority, they bear a natural obligation to prioritise the patient's well-being and handle their authoritative position conscientiously. These physicians emphasised the importance of managing their power with integrity within the physician-patient encounter. The study provided insights into the nature of power dynamics within the patient-provider relationship (Nimmon & Stenfors-Hayes, 2016), which can inform efforts to improve healthcare outcomes and patient satisfaction with their healthcare providers (Dickerson, 2022).

Similarly, in the realm of shared decision-making within paediatric practice, a review identified the presence of a power imbalance as a barrier. This challenge impacted both children and parents, necessitating proactive efforts from healthcare providers to encourage and support their active participation in decision-making (Boland et al., 2019). This power dynamic is also observed in the field of mental health, where traditional and imbalanced patient-provider relationships persist (Aoki, 2020).

Beyond power distance, two additional cultural values, individualism and collectivism, offer valuable insights into our comprehension of patient-provider relationships. As highlighted by Yates and De Oliveira (2016), individualistic cultures emphasise individual autonomy, considering each person as a separate entity with distinct characteristics and the ability to make independent choices. These cultures prioritise personal goals and self-expression rather than conforming to the goals of others (Yates & De Oliveira, 2016). Uniqueness is highly valued in such societies. On the other hand, collectivistic cultures perceive the self as interconnected with the larger group. Individuals are expected to collaborate with their social and family group towards shared objectives, adapt their behaviour to fit social contexts, and strive for group harmony rather than personal pursuits (Yates & De Oliveira, 2016). In other words, cultures with more greater individualistic values such as the US or Germany place more emphasis on individual autonomy and personal goals rather than collective goals, while cultures with greater collectivist values such as Venezuela and India place more emphasis on the importance of the group and working towards shared objectives (Guess, 2004).

Asian countries are often perceived as being closer to collectivism than individualism, which impacts important elements of PCC. For instance, in a comparative study analysing doctor- patient communication styles, the US was compared to three Asian countries:

Pakistan, Japan, and Thailand (Matusitz & Spear, 2015). The findings revealed that the doctor-patient communication styles in Pakistan, Japan, and Thailand tend to be more hierarchical and paternalistic when compared to the United States. In cultures that prioritise individualism, the focus is on patients' goals and their right to have control over their healthcare decisions (Matusitz & Spear, 2015). In contrast, in collectivist cultures such as in Asian countries, patients are viewed as subordinates to doctors and as part of a larger group. It is evident that a patient's perception of sickness and health, and their own role in this is closely linked to the cultural context in which they reside. Moreover, the implementation of a PCC approach in Asian countries encounters various obstacles rooted in cultural, religious, social, philosophical, and practical factors, necessitating careful consideration (Matusitz & Spear, 2015).

Another study suggested that different relational contexts also impact the involvement of families in care, which can temper the impact of culture. In a study conducted across seven countries (Australia, China, Malaysia, India, South Korea, Thailand, and the US) to investigate the preferred level of family involvement in medical decision-making, it was reported that participants who preferred higher self-involvement (i.e. more individualistic approaches) also tended to desire lower family involvement (Alden et al., 2018). The authors argue that cultural influences might not play a significant role in determining family involvement preferences. Instead, they suggest that relational interdependences and a desire for self-involvement are the most important factors influencing the desire for family involvement. As a result, making assumptions based on culture about the preference for family involvement should be avoided during medical decision-making, and the attitudes of individual patients taken into account to ensure more effective patient-centred care. Overall, these findings underscore the importance of both cultural and individual factors in shaping patient-provider interactions and highlight the need for interventions that

address power dynamics, foster open communication, and promote patient-centred care across different cultural contexts.

In collectivist societies, where decisions are primarily made by the family, the family-patient- healthcare provider dynamic can be a double-edged sword—acting as both a barrier and a facilitator to decision-making (Alshahrani et al., 2018; Baig et al., 2020; Obeidat & Lally, 2018). Families can play a helpful role in managing a patient's condition. For instance, a 2010 study in the US examined family support and family-related barriers to self-care among functionally independent adults with diabetes or heart failure (Rosland et al., 2010). The study revealed that family support was associated with better self-management adherence, while family barriers were linked to worse adherence (Rosland et al., 2010). While family involvement in care often has a positive impact, it's worth noting that families can sometimes disrupt the patient's treatment plan, which can hinder the patient's active involvement in their care. Studies conducted in Australia and Jordan have shed light on instances where families were reported as acting as barriers to patient involvement in decision-making, occasionally taking over the decision-making process (Obeidat & Lally, 2018; Shepherd et al., 2008). This often results in the family taking precedence over the patient's autonomy in making informed health-related decisions (Alfahmi, 2022). This suggests that there is a complex relationship between patient family authority and the patient's rights to autonomous decision-making in their health. Consequently, any initiatives aimed at encouraging patients to take an active role in decision-making should carefully consider the influence of the patient's family within the decision-making process (Obeidat & Lally, 2018).

To overcome cultural barriers to the implementation of PCC, Ishikawa and Yamazaki (2005) point out that to enhance communication in patient-provider interactions and

promote mutual participation, it is crucial to customise communication training programs and interventions for both healthcare providers and patients to align with their respective cultural backgrounds. By tailoring these programs in a culturally appropriate manner, the patient-provider interaction will improve. Rather than solely emphasising patient autonomy, embracing a model of mutual participation in the patient-physician relationship is important. However, for this model to be beneficial to patients and physicians, it must be implemented within the context of social and cultural norms.

The research presented in this thesis is situated in Saudi Arabia, a nation known for its unique culture. Saudi culture is distinctively collectivist, emphasising strong family bonds (Alfahmi, 2022; Almutairi & McCarthy, 2012). In this Saudi context, the family unit carries immense significance, and healthcare decisions are typically reached through a collective process involving input from family members (Halligan, 2006). This approach to healthcare decisions aligns with the broader collectivist culture, where patients are considered interconnected with their families. Furthermore, Saudi culture highly values the authority and expertise of physicians (Banaser et al., 2017). This trait is deeply embedded in the culture of Muslim countries (Abdulhadi et al., 2007). Therefore, investigating patient-centred care within the Saudi Arabian context takes on particular significance due to these cultural norms.

Understanding how PCC functions within this collectivist culture is essential. It not only aids healthcare providers and policymakers in developing strategies to ensure the effectiveness of patient-centred care but also ensures that it is culturally sensitive. These strategies may encompass educating healthcare providers on patient involvement, fostering active patient participation in care, exploring alternative methods for patient involvement, acknowledging the importance of communities, and creating an enabling and supportive

environment (World Health Organization, 2016b).

Conclusion

The literature clearly shows a growing global interest in implementing and practising the PCC approach. This interest is driven by the recognition of the various benefits associated with delivering care through this model, including improvements in the quality of care and patient satisfaction. The increasing trend in PCC adoption is, in part, a response to past violations of human rights, such as unethical experiments, emphasising the need for a more patient-centric approach. In response to this growing interest, many organisations have developed guidelines for PCC practice, with Western culture serving as the primary influence. However, it's worth noting that there is no corresponding organisation based in the Middle East dedicated to PCC, while many healthcare institutions in the region have been accredited by western organisations such as the Planetree organisation. This discrepancy highlights the need for cultural adaptation and context-specific approaches to PCC implementation.

Despite the increased awareness of the importance of PCC in the international literature, certain barriers persist, particularly concerning healthcare providers' knowledge and attitudes toward PCC. These barriers underscore the need for ongoing training in interpersonal skills and PCC to bridge the gap between knowledge and practice. Notably, there is a scarcity of studies that assess both healthcare provider and patient perspectives on the concept of PCC, warranting further research in this area.

The practice of PCC varies between Western and non-Western countries due to the significant influence of culture on how patients perceive their role in healthcare. In collectivist countries, cultural factors play a pivotal role in shaping patient preferences for involvement in decision-making. The absence of a PCC model based on the collectivist

approach in these countries may contribute to these differences. To further advance the understanding of the relationship between culture and patient-centred care, additional research is needed. Exploring PCC in diverse cultural contexts can offer valuable insights. Drawing examples of PCC practices from other countries can serve as useful tools for guiding the implementation of PCC in developing nations, especially in the Middle East, by tailoring these practices to the cultural norms and values of the local population. In the next chapter, Chapter 3, I discuss the methods employed in this thesis. It provides a comprehensive overview of the mixed methods approach used, along with the rationale for choosing this particular method. Ethical considerations relevant to this project are also presented, alongside a detailed description of the data analysis process.

CHAPTER 3

METHODOLOGY

Introduction

This chapter details the aims of the research and describes the methods used to achieve these aims. The discussion in this chapter is supplemented by the specific methods provided in each of the results chapters. Those chapters are structured as journal articles and therefore contain shorter but specific methods information. This current chapter looks more holistically at the methodology employed in the thesis. It includes a brief description of the project research aims and the development of the research question and the research design with a focus on the philosophical worldviews underpinning the project. In doing so I focus on the development and purpose of mixed method approaches, types of mixed method designs, and a rationale for using mixed methods in this project. I also discuss ethical considerations relevant to this thesis. Finally, descriptions of the quantitative and qualitative sampling, data collection and data analysis approaches taken are provided.

Research aims and research question development

As introduced in the first chapter, the overarching aim of this thesis is to inform the policies guiding patient-centred care in Saudi Arabia by exploring diabetic patients' and healthcare providers' perspectives of PCC. In order to refine this aim and develop the research questions, a systematic literature review was undertaken. This aimed to summarise available and reliable evidence which would help to identify the existing research and gaps within this research. It explored the current state of knowledge in the practice of PCC in the MENA region and clarified what was known and what this current project should explore in response

(Clarke, 2011; Petticrew & Roberts, 2006). Mulrow (1994) described three premises for conducting a systematic review: (1) reduce the amount of information to be extracted into a manageable form; (2) aggregate critical pieces of information for decision-making and (3) allow policymakers to formulate guidelines and legislation. In relation to this thesis, the systematic review aimed to collect essential information regarding the practice of PCC in the Middle East and North African region. Findings from this systematic review are presented in Chapter 4. Its findings demonstrated that there was very little existing literature on PCC in Saudi Arabia. It therefore helped to shape the research project around an exploration of the different perspectives of patients and healthcare providers to provide an understanding of the nature of patient-centred care practice in Saudi Arabia.

Based on this systematic review, the thesis aims were refined, and the research focused around the following aims:

1. What is the current form of patient involvement in healthcare practice in Saudi Arabia?
2. How do healthcare providers enable and empower patient involvement in health encounters?
3. What model is most appropriate for improving patient involvement in practice in Saudi Arabia?

The focus on a diabetic population was identified as relevant due to the increasing prevalence of diabetes in Saudi Arabia (Naeem, 2015) and the serious complications associated with this disease (World Health Organization, 1999), which require increased management of the health impacts of diabetes and adoption of a healthy lifestyle (Nam et al., 2011). The effectiveness of these health strategies depends upon the involvement of patients in care (Nam et al., 2011), so that patients must be in a position to be able to make serious decisions

regarding their health and also to communicate with different healthcare providers. These ongoing interactions with healthcare providers also places patients in a position where they can reflect on their experience of involvement in care, thus they are good candidates to be informed participants for the research (Entwistle et al., 2008; Funnell, 2004).

Research design

Philosophical worldviews

Research paradigms are linked to worldviews (Creswell & Creswell, 2018). Worldviews can be defined as "sets of beliefs and practices, shared by communities of researchers, which regulate inquiry within disciplines" (Weaver & Olson, 2006, p. 460). Research worldviews are essential because they provide a framework for researchers to understand and approach their research questions, identify the appropriate methods, techniques, and tools to use in the research, and the assumptions and beliefs that underlie their research. It is therefore an important aspect of the research process that can help to ensure that research is conducted in a rigorous and systematic manner (Bergman, 2010; Kivunja & Kuyini, 2017). There are four main research paradigms: positivist, constructivist, transformative, and pragmatist (Creswell & Creswell, 2018). Each paradigm is characterised by ontological, epistemological, and methodological approaches which shape how researchers conceptualise and conduct research, and how the research contributes towards disciplinary knowledge construction (Bunniss & Kelly, 2010).

Creswell and Creswell (2018, p. 44) state that the positivist paradigm, "...reflect[s] a deterministic philosophy about research in which causes probably determine effects or outcomes. Thus, the problems studied by post positivists reflect the need to identify and assess the causes that influence the outcomes, such as found in experiments" . This paradigm is based on a belief that reality exists independently of humans, and is linked to the

ontological position of realism (Rehman & Alharthi, 2016). The epistemological position is objectivism, in which the researcher is an objective observer whose actions do not have any effect on what is being observed (Rehman & Alharthi, 2016). It involves a process of experiments to explore and answer the research question based on measurable outcomes (Kivunja & Kuyini, 2017). According to Kivunja and Kuyini (2017), in the positivist paradigm, conclusions are drawn through the formulation of hypotheses, testing of hypotheses, and formulation of mathematical equations, calculations, extrapolations, and expressions.

The interpretivist paradigm/ constructivist paradigm "...hold[s] the assumption that individuals seek understanding of the world in which they live and work. Individuals develop subjective meanings of their experiences which are directed toward certain objects or things" (Creswell & Creswell, 2018, p. 46). This paradigm rejects the idea that there is only one reality which is observable and exists independently of humans. Instead, this approach positions realities as multiple, socially constructed and created, rather than discovered (Rehman & Alharthi, 2016). The epistemological position is subjective (Rehman & Alharthi, 2016). In other words, reality is perceived subjectively, and the research accounts for this by encompassing meanings and understandings of social and experiential aspects (Alharahsheh & Pius, 2020). The researchers working within this paradigm try to understand the participants' points of view and interpretation of the world around them. Researchers understand that they create meaning from their data through their own thinking, and construct new knowledge based on their interactions with the participants (Kivunja & Kuyini, 2017).

The third paradigm is the critical or transformative paradigm, which holds a philosophical position in which the researcher identifies one of the qualitative frameworks (e.g., indigenous populations, females, racial and ethnic groups, people with disability, and so forth) and uses

the framework to advocate for the underrepresented populations and to help create a better, just society for them (Creswell & Creswell, 2018). This paradigm is suitable for research into social justice, political and economic problems, as it aims to change policies and improve social justice. Therefore, the type of research in this paradigm incorporates an action agenda for reform which provides participants with the opportunity to have a voice in the research (Kivunja & Kuyini, 2017). The participants will often also collaborate on the research design itself, by assisting the researcher to develop research questions, collect data, and analyse information (Creswell & Creswell, 2018). Furthermore, this paradigm assumes a transactional epistemology which focuses on establishing relationships between the researcher and the respondents (Kivunja & Kuyini, 2017) while the ontological position of this paradigm holds that "...reality is socially constructed, but it does so with the conscious awareness that certain individuals occupy the position of greater power than that individuals with other characteristics may be associated with a higher likelihood of exclusion from decisions about the definition of the research focus, questions, and other methodological aspect of the inquiry" (Mertens, 2007, p. 216). In this sense, this paradigm focuses on meeting the needs, rights, and freedoms of marginalised groups within society.

The fourth worldview is the pragmatic approach. The pragmatist paradigm is considered the best philosophical approach for combining both quantitative and qualitative methods in one research design (Creswell & Plano Clark, 2011; Datta, 1994; Migiro & Magangi, 2011). This paradigm is therefore associated with mixed methods research and has emerged as an alternative to both positivism and interpretivism (Halcomb & Hickman, 2015; Wheeldon, 2010). The researcher relies on both objective and subjective approaches to answer the research question (Halcomb & Hickman, 2015). This paradigm focuses on research problems using any relevant approaches available, whether they be qualitative or quantitative, to derive appropriate knowledge of the phenomenon under investigation (Creswell, 2008). This

paradigm uses abductive reasoning to analyse the data and answer the research questions rather than relying on deductive and inductive reasoning (Feilzer, 2010; Migiro & Magangi, 2011). This approach allows explanations and hypotheses to develop through the research process based on the researchers' expertise, experience, and intuition (Wheeldon, 2010).

Based on the features of each paradigm, the pragmatist paradigm appears the most suitable for this research. The pragmatist paradigm is characterised by its focus on the use of any relevant approaches, whether qualitative or quantitative, to address research questions and derive appropriate knowledge. Pragmatism emphasises the combination of different methods to gain a comprehensive understanding of the phenomenon under investigation.

Research designs

Research describes a process of collecting and analysing information to gain an understanding of a phenomenon (Creswell, 2012). This process generally consists of three essential steps; development of research questions, collecting data in relation to these questions, and providing answers to the questions posed. The outcome of research is new knowledge or information which can increase understanding, improve practice, and inform policy (Creswell, 2012).

Research design is described by Creswell and Creswell (2018) as the type of research approach taken to set the direction and procedures for a research study. It serves as a connection between the research questions or hypothesis and the implementation of the research (Durrheim, 2004; Maurtvedt, 2006). Broadly, there are three types of research design: quantitative, qualitative, and mixed methods, and each has its own philosophical assumptions (Creswell, 2008, 2012; Creswell & Poth, 2018; Edmonds & Kennedy, 2017; Halcomb & Hickman, 2015). Quantitative research is "...an approach for testing objective theories by examining the relationship among variables. These variables, in turn, can be

measured, typically on instruments, so that numbered data can be analysed using statistical procedures" (Creswell & Creswell, 2018, p. 41). The second approach, qualitative research, primarily provides "...an approach for exploring and understanding the meaning individuals or groups attribute to a social or human problem" (Creswell & Creswell, 2018, p. 41). The third research design, mixed methods, is an approach to inquiry that combines both qualitative and quantitative forms of research. It involves philosophical assumptions, the use of qualitative and quantitative approaches, and the integration of both approaches within a study (Creswell & Creswell, 2018).

This thesis provides an in-depth analysis of patient and healthcare provider perspectives about their involvement in patient-centred care using mixed methods. The choice to use this approach to data collection is further described below.

Mixed methods

The development of mixed methods research

Mixed methods research combines quantitative and qualitative approaches to data collection and analysis within either a single study (Creswell, 2011; Halcomb & Hickman, 2015; Leavy, 2017) or multiple phases of a series of studies (Creswell, 2012). This type of research has become popular particularly within health services research (Tariq & Woodman, 2013) due to the limitations of using qualitative or quantitative methods alone (Doyle et al., 2009; Edmonds & Kennedy, 2017). This has, however, led to a debate amongst the proponents of both quantitative (positivist) and qualitative (constructivist) research who have argued the superiority of their approaches. Methodological purists claim the incompatibility of combining the two approaches and argue that research should be purely quantitative or qualitative due to the fact that each approach has its own philosophical assumptions

(Bergman, 2011; Creswell, 2011; Gunasekare, 2015). They question whether it is possible to combine a perspective that emphasises objectivity with another emphasising subjectivity (Bergman, 2011). In response to this argument, Gunasekare (2015) and Creswell et al. (2011) argue that the different philosophical assumptions brought together in mixed methods research create new knowledge and improve research quality. In addition, Halcomb and Hickman (2015) add that mixed methods can generate more comprehensive insights into the phenomenon under investigation and offers a better approach than using quantitative or qualitative methods alone.

Creswell and Clark (2017) draw together the advantages of using both quantitative and qualitative approaches in mixed methods research including: strengthening and overriding the weaknesses associated with either approach alone, providing more evidence to solve a research problem compared with a solely quantitative or qualitative approach, allowing the researcher to utilise multiple worldviews, and providing the researcher with the flexibility to employ complementary methods to investigate a phenomenon. The flexibility of mixed methods approaches is also more highly adapted to exploring the complexity of social phenomena (Creswell et al.; 1997). However, despite these advantages there are several challenges associated with the use of this approach. It requires extensive data collection, familiarity and experience with both approaches, and it is time-consuming to conduct both qualitative and quantitative analyses (Creswell & Creswell, 2018).

Combining both qualitative and quantitative data is useful in the sense that it produces more knowledge to inform theory and practice, and hence it may increase the generalisability of the findings (Johnson & Onwuegbuzie, 2004). Linked to this, one of the main purposes of conducting mixed methods research is *triangulation* (Hesse-Biber, 2010). Triangulation aims to evaluate the consistency of the results obtained in the research by approaching the

questions using different tools (Migiro & Magangi, 2011). According to Hesse-Biber (2010), comparing the data from these different approaches via triangulation therefore enhances the credibility of the research results and enriches the research conclusion.

Another reason to incorporate mixed methods into a research project is *complementarity*, in which multiple methods help the researcher to gain a broader understanding of the research problem or to clarify the results from one method using the results from other methods (Hesse-Biber, 2010; Johnson & Onwuegbuzie, 2004). Furthermore, employing a mixed method design helps in *developing* the research where the findings from one method helps to inform the development and implementation of the other method. This is more appropriate within sequential mixed methods designs. For example, using semi-structured interviews and then using these qualitative findings to create a quantitative questionnaire (Greene et al., 1989; Hesse-Biber, 2010). Mixed methods can also be used for *initiation*, where a researcher seeks to discover a new perspective using one method and then conducts another investigation using another method, which can increase the breadth and depth of the study findings. For example, study results might give rise to a contradiction which requires clarification, and this may therefore initiate a new study (Greene et al., 1989; Hesse-Biber, 2010). Finally, use of mixed methods leads to *expanding* the breadth of the research scope through producing comprehensive results, facilitating future research and allowing researchers to utilise mixed methods to investigate the research problem (Hesse-Biber, 2010).

Types of mixed methods designs

There are three primary types of mixed method designs; 1) concurrent design, 2) explanatory sequential designs, and 3) exploratory sequential designs (Creswell & Creswell, 2018). These designs differ based on timing, priority, integration, and theoretical perspectives (Andrew & Halcomb, 2009; Creswell et al., 2003; Halcomb & Hickman, 2015; Hayes et al., 2013). The

concurrent mixed method design is a single phase approach used to collect both quantitative (quan) and qualitative (qual) data simultaneously, from which findings are then analysed and compared (Creswell & Creswell, 2018). Results from both sets of data are equally prioritised (QUAN + QUAL) (Hayes et al., 2013). The second design, explanatory sequential design, involves two phases of data collection where data are collected sequentially and priority given to the quantitative phase (QUAN → qual) (Hayes et al., 2013). Researchers first collect the quantitative data and use the results to inform the second qualitative phase. The third type of design, exploratory sequential design, is the opposite of the explanatory design, and priority is given to the qualitative phase (QUAL → quan). This approach involves three phases. In the first phase, the researcher collects and analyses the qualitative data. Then, based on the findings, they develop a quantitative aspect such as collection of new variables or an experimental intervention. Finally, the researcher tests the quantitative aspect of the project (Creswell & Creswell, 2018). Each of these sequential methods have different durations based on the number of phases (Hayes et al., 2013). This thesis utilised a concurrent mixed method design, as justified below.

Rationale for using mixed method research

A concurrent mixed methods design (QUAN + QUAL) was selected for this program of research to explore patients' perspectives on their involvement in care in Saudi Arabia. The decision to use this method was based on several factors. First, based on the results of my systematic review (explored in Chapter Four), there are a limited number of existing studies conducted in Saudi Arabia on the topic of patient involvement in healthcare. In addition, no existing studies appear to have been conducted on diabetic patients within Saudi Arabia. Hence, combining both quantitative and qualitative methods have greater power for providing a broad initial understanding of the research problem but within a defined patient group. The

use of this approach allowed me to produce data from multiple sub-studies that could be combined for interpretation. The combination of both quantitative and qualitative elements in parallel data collection compensates for the weaknesses of either method and strengthens the knowledge of the topic under investigation (Hayes et al., 2013). Hence, using this approach provided information that enabled me to gain a better understanding and a broader perspective on the topic. In addition, this approach requires a shorter duration for data collection in comparison to sequential approaches, reinforcing my decision to use this method.

Ethical considerations

Ethical requirements for research have changed over time due to increasing concerns about research limitations and legislative changes around human rights and data protection, especially with the development of increasingly complex technology (Parveen & Showkat, 2017). Researchers involving human participants in a study must consider the ethical issues surrounding their research (Polit & Beck, 2017) due to the fact that studies involving humans participants may pose risk to participants' health and well-being, ranging from minor discomfort to major risks such as physical or mental harm (Marczyk et al., 2005). Prior to the advancement of formal research ethics guidelines, an absence of regulations regarding human participant in research (Artal & Rubenfeld, 2017) led to many unethical studies such as the Tuskegee Syphilis experiments in the US (Greaney et al., 2012) and the medical experimentation in Nazi Germany (Fisher & Anushko, 2008). In recognition of this misconduct, guidelines were developed to provide clarity around the ethical principles which must be considered when conducting research. These regulations include the Nuremberg Code (1947), the Declaration of Helsinki (1964), and the Belmont Report (1979). All of these documents provide general guidelines for conducting research with human subjects (Neff,

2008). For this study, all of these ethics principles were followed. The following section addresses how these principles were addressed in this research.

The Institutional Review Board (IRB)/Human Research Ethics Committee (HREC) approval

The role of the IRB or HREC is to ensure that the research plan meets the ethical requirements set out in relevant ethical guidelines (Polit & Beck, 2017). The ethical guidelines are set out in the National Statement on Ethical Conduct in Human Research. Under these guidelines, the researcher must comply with the requirements listed in the National Statement, which includes that any research involving humans or their data must be reviewed by an HREC committee. This review focuses on the research design, recruitment plan, informed consent process, protection provided to the research participants and the manner in which participants' rights are respected (Greaney et al., 2012). In this current study, ethical approval was obtained from the University of Sydney Human Research Ethics Committee (**Appendix A**). Approval was also obtained from the Saudi Arabia Directorate of Health Affairs Taif Institutional Review Board (**Appendix B**).

Non-Maleficence/Beneficence

According to Polit and Beck (2017), the researcher should act to minimise the risk (non-maleficence) and maximise potential benefits (beneficence) to research participants and to the community. Researchers should consider any potential harms posed by the research including physical, emotional, social, and financial harms (Greaney et al., 2012; Polit & Beck, 2017). As this study explores patient and healthcare provider perceptions of patient involvement in care, no expected harms or discomfort were identified as likely to arise from participant involvement in the quantitative studies. However, the possibility of distress was identified as likely to rise from participating in interviews. The Participant Information Statements (PIS)

(**Appendix C and D** contain both English and Arabic versions), provided to participants in this study outlined the potential risks involved in participating in the research. One such risk is the possibility of experiencing distress when recalling past experiences where healthcare professionals did not communicate with participants in the way that they desired. Although this risk is considered to be small, participants were informed that they could contact King Abdul-Aziz Specialist Hospital via telephone for assistance if they were to experience distress during the study. A social worker would be available to assess the participant's level of distress and provide appropriate support.

Confidentiality and Anonymity

The concepts of confidentiality and anonymity are related in the sense that they both protect the privacy of the participant (Wiles et al., 2008). Anonymity involves hiding research participants' identities so that they are not revealed in either data collection nor in reporting (Vainio, 2013). In contrast, confidentiality means assuring that any information provided by the research participants will not be accessible to non-authorised people (Polit & Beck, 2017). Therefore, providing anonymity also assures confidentiality. For the qualitative study, involving interviews, confidentiality but not full anonymity in data collection was achievable (Hawthorne et al., 2012; Polit & Beck, 2017), thus participants were assured that only the research team would have access to their identifiable information. The confidentiality of participant data was maintained as follows: use of a secure transcription service operating under Australian privacy legislation, interview recordings were destroyed after they were transcribed, and all private data were removed. Codes used to refer to participants, and any potentially identifying information (e.g., names of third parties) was removed from transcripts. Confidentiality was also maintained through structured data protection processes. I utilised the university OneDrive to store and share the data related to the project. OneDrive

is a highly secure data management service recognised and managed as a preferred storage facility by the University of Sydney. Participants in the study were informed that the data storage and disposal would be in accordance with the National Statement on Ethical Conduct in Human Research (2007).

Informed consent

Informed consent is an essential element of ethical research. It requires that participants only consent to participate in research if they have knowledge of what the proposed research will entail, comprehension of that information, and the ability to consent or decline to participate voluntarily (Fisher & Anushko, 2008; Polit & Beck, 2017). Consent forms were used in all interviews for this research and indicate that participants acknowledge this informed consent and that they are happy to participate in the research based on the information that they have received. This information was provided for this research via participant information statements (**Appendix C and D**), which participants read prior to signing the consent form. The PIS included information on the research team, the sponsoring institution, the purpose of the study, benefits for participants, the level and type of participant involvement, any potential risks to participants, the confidentiality of participant information and assurance that participants can withdraw consent to participate until the interview is complete, and if they do so, all information collected until that point will be erased . The statement provided to patients was translated into Arabic in simple language while the healthcare provider statement was written in simple English. For the quantitative research via surveys, the PIS was provided but no consent form was required. Instead, their completion and submission of the questionnaire was considered a form of consent. However, for the qualitative study, direct informed consent through signing a consent form was a requirement. The patient PIS and informed consent forms were translated from English to Arabic by a certified translator.

Voluntary participation

Voluntary participation is the practice whereby potential participants can voluntarily decide to participate in the study. This process involves participants having the right to ask questions, refuse to provide information and the ability to withdraw at any time (where feasible) from the study (Polit & Beck, 2017). Accordingly, for both qualitative and quantitative studies, the PIS provided by the researcher included the following statement: 'Being in this study is completely voluntary and you are not required to take part in the study'. The participant information statements for both patients and healthcare providers are included in **Appendix C and D** and **Appendix E**, while the participant consent form for the qualitative research is included in **Appendix F and G** for both English and Arabic versions.

Sampling

Sampling is an essential part of the research process (Creswell & Clark, 2017). In academic research there are two main techniques to recruit participants into research: random sampling and non-random sampling (Creswell & Clark, 2017; Vanderstoep & Johnson, 2008). In random sampling, each individual in the population of interest has an equal likelihood of being selected to participate in the study (Creswell & Clark, 2017; Vanderstoep & Johnson, 2008). In contrast, in non-random sampling, participants are selected based on their characteristics or their availability to participate in the study, thus individuals do not have an equal likelihood of participating in the study (Vanderstoep & Johnson, 2008). Non-random sampling includes convenience, quota, consecutive, and purposive methods (Polit & Beck, 2017). For this study, several sampling techniques were employed including a purposive sampling method which was utilised to select information-rich subjects who have experienced the phenomena being investigated in the study (Leavy, 2017). A convenience sampling method was utilised to gather information from participants who are easily

accessible to the researcher and readily available to participate in the study (Etikan et al., 2016). In addition, snowball sampling methods were used, which allowed participants to recruit other potential participants meeting inclusion criteria into the study (Allen, 2017).

Sample size

In quantitative research, obtaining an adequate sample size is vital to ensuring adequate power for investigating the research question and in validating the study (Polit & Beck, 2017). To determine the sample size, I hypothesised that there are similarities in patients' and healthcare providers' perceptions of PCC based on findings of previous studies (Al-Tannir et al., 2017; Bodegård et al., 2019; Medina-Artom & Adashi, 2020) and therefore employed two one-sided equal-variance t-tests to calculate the required sample size to test for equivalence between groups. The analysis revealed that a sample size of 129 in each of the two groups (diabetic patients and healthcare providers) was required to establish a finding of equivalence between the groups with 80% power and a 5% significance level. However, due to the impact of Covid-19 and low response rates, this sample size was not able to be recruited. Recruitment was stopped after 9 months of data collection (1 January to 30 September 2022), with a total of 116 individuals living with diabetes and 116 healthcare providers recruited into the study. While both studies ended up with 116 participants the matching numbers of participants were a mere coincidence, rather than deliberate design.

Data collection methods

To gain better understanding of the nature of PCC in Saudi Arabia the current study used online questionnaires and semi-structured interviews with patients, and online questionnaires with healthcare providers.

Patient recruitment

For the quantitative study of patients' experiences of PCC, an invitation letter was sent to diabetic patients receiving treatment at a diabetic centre at King Abdul-Aziz Specialist Hospital in Saudi Arabia by healthcare providers working within the centre through a message via the WhatsApp messaging application. The message directed them to fill in the survey which was hosted on Qualtrics. Participants were also asked to refer the study to other patients who met the inclusion criteria. The data collection was conducted from January to June 2022. No explicit consent was sought from the participants; instead, the completion and submission of the questionnaire were considered to constitute consent. Recruitment to the qualitative phase of the data collection was conducted through the survey, as survey participants were asked within the survey if they wanted to participate in an interview. Participants who indicated their interest to participate in the interview received an information statement and the consent form. Interviews were conducted between February and March 2022.

Healthcare provider recruitment

A letter of invitation was sent to healthcare providers by the hospital on behalf of the research investigator. Participants then filled in the online survey, which was hosted on Qualtrics. Data were collected between January and September 2022. Completion of the questionnaire was considered to be informed consent to participate in the study.

Quantitative data analysis

Reliability and validity of the questionnaires

Validity and reliability are important indicators of the quality of the data collection instrument (Kimberlin & Winterstein, 2008; Sürücü & Maslakçi, 2020). Both concepts are

interconnected due to the fact that a measurement cannot be valid unless it is reliable (Marczyk et al., 2005). Reliability refers to the consistency or dependability of a measurement instrument (Marczyk et al., 2005). Reliability can be measured through different approaches, including test-retest reliability, inter-rater reliability, intra-rater reliability, and parallel test reliability (Devon et al., 2007; Marczyk et al., 2005; Polit & Beck, 2017). The internal consistency reliability can be measured by item homogeneity, which means the degree to which the items on a test measure the same construct (Henson, 2001) and is thus connected to the inter-relatedness of the items within the test (Tavakol & Dennick, 2011). The most frequent measure used to assess internal consistency is the Cronbach's Alpha coefficient (α) (Devon et al., 2007; Kimberlin & Winterstein, 2008; Polit & Beck, 2017; Taherdoost, 2016; Tavakol & Dennick, 2011), with a range from 0.70 to 0.95 indicating an acceptable degree of internal consistency (Tavakol & Dennick, 2011).

As a separate concept, validity may be defined as "...what the test or measurement strategy measures and how well it does so" (Marczyk et al., 2005, p. 106). Thus an instrument is considered valid when it actually measures what it is intended to measure (Marczyk et al., 2005). Thus validity is about the truthfulness of the instrument (Vanderstoep & Johnson, 2008). The literature on research methodology identifies several types of validity, including face validity, content validity, construct validity and criterion validity (Creswell, 2008; Creswell & Creswell, 2018; Leavy, 2017; Taherdoost, 2016; Vanderstoep & Johnson, 2008). Face validity refers to whether the measurement actually measures what it reports that it measures (Polit & Beck, 2017), while content validity refers to the extent to which the content of a measurement measures what it is intended to measure (Kimberlin & Winterstein, 2008; Taherdoost, 2016). This type of validation requires consultation with experts to determine the relevance, comprehensiveness, and balance of the measurement content (Polit & Beck, 2017). Construct validity is another method used to assess the validity of an

instrument. This concept refers to the consistency between the study's results and the theoretical foundations guiding the research and is associated with interpreting the basis of the causal relationship (Kazdin, 2003; Marczyk et al., 2005). This type of validity is an assessment based on the accumulation of data from several studies using a particular measuring instrument (Kimberlin & Winterstein, 2008). Lastly, criterion validity is "the extent to which a measure is related to an outcome" (Taherdoost, 2016, p. 32). In other words, it deals with the relationship between scale scores and some specified, measurable criterion (Pallant, 2020).

In this current study, I assessed the content validity of the translated patient questionnaire by consulting two experts in the field of Arabic literature and applied linguistics. The experts were asked to check the clarity and the relevance of the questionnaire. In addition, the questionnaire was pilot tested on thirteen diabetic patients, and the internal consistency of the tool tested using Cronbach's alpha. An *acceptable* internal consistency of the sixteen items was confirmed by a Cronbach's alpha coefficient score of 0.840.

Descriptive statistics

The purpose of descriptive statistics is to "summarise or describe the distribution of values for a set of observations" (Crocker & Algina, 1986, p. 16). There are three primary categories of descriptive statistics: measures that determine frequency and percentage, measures that establish central tendencies such as mean, median, and mode, and measures that ascertain dispersion or variability including variance, standard deviation, standard error, quartile, interquartile range, percentile, range, and coefficient of variation. These statistics offer concise summaries about samples. Measures of frequency, mode, median, range and interquartile range typically apply to categorical data, whereas measures of mean, variance and standard deviation are employed for continuous data (Mishra et al., 2019). For this

research, descriptive statistics were employed to describe the participants' sociodemographic characteristics, including both categorical and continuous variables.

Inferential statistical analysis

Inferential statistics are designed to "test hypotheses about whether or not a given sample of observations has been obtained from a population with certain distributional characteristics" (Crocker & Algina, 1986, p. 16). In this program of study, parametric methods were employed under the properties of the central limit theorem assumption. The central limit theorem states that "...the average of a large number of independent random variables is approximately normally distributed around the true population mean" (Lumley et al., 2002, p. 152). According to Allende-Alonso et al. (2019), when the sample size is sufficiently large, typically exceeding 30 or 40, any deviations from the assumption of normality are unlikely to lead to significant issues. Given adequate sample size, I followed the assumption that the mean of collected data was normally distributed. To examine for differences in outcomes between demographic categories, I employed Student's t-test and analysis of variance (ANOVA) tests, which are both statistical methods used to compare groups. Student's t-test is used to compare mean scores for a continuous outcome between two groups (Marczyk et al., 2005), while the ANOVA test is designed to compare mean scores between three or more groups with regard to a selected reference group (Pallant, 2020). Both tests rely on key assumptions, including outcomes in each group following an approximately normal distribution, independence of observations, equivalence of variances between groups, and that observations in each group are randomly sampled (Weaver, Morales, et al., 2017a; Weaver, Morales, et al., 2017b). Statistical significance was considered to have been achieved if the p-value (p) for any test was less than 0.05. According to (Nayak & Hazra,

2011), a value < 0.05 is an indication of significant differences in the mean score between groups.

For examining associations between two continuous or ordinal variables, a correlation coefficient test is typically used (Khamis, 2008). I employed the Pearson's (r) product-moment correlation coefficient and Spearman's rank correlation coefficient (r_s) to test for significant correlations between continuous variables. The Pearson's correlation coefficient is a parametric test (Polit & Beck, 2017) commonly used for comparing two continuous variables, and it can also be applied to situations involving one continuous variable and one dichotomous variable (Pallant, 2020). It quantifies the strength and direction of the linear relationship between these variables (Rebekić et al., 2015). The assumptions for Pearson correlation analysis encompass several critical criteria: First, both variables being examined must be measured at the interval or ratio scale. Second, a linear relationship exists between the two variables. Third, the dataset should be devoid of significant outliers, which are individual data points that deviate from the typical pattern. Lastly, data should exhibit a normal distribution (Obilor & Amadi, 2018).

In contrast, Spearman's rank correlation is specifically designed to serve as an alternative when some of the assumptions for a Pearson correlation are violated (Pallant, 2020; Polit & Beck, 2017) and is designed for variables measured on an ordinal scale or ranked data (Pallant, 2020; Polit & Beck, 2017). Rather than requiring a linear relationship, the Spearman correlation evaluates the strength and direction of the monotonic relationship between two variables (Rebekić et al., 2015). Unlike the Pearson's correlation, Spearman's rank correlation does not require the variables to follow a normal distribution or exhibit homoscedasticity (Weaver, Morales, Dunn, & and Weaver, 2017). However, there are specific prerequisites for using Spearman correlation: the variables can be ordinal, interval, or ratio, the data must

exhibit monotonicity, and the observations should be randomly collected from a population (Weaver, Morales, Dunn, & and Weaver, 2017).

Correlation coefficients from these tests provide information about the direction of the relationship, whether it is positive or negative. The size of the correlation can range from (-1 to +1) which represents the direction of the relationship. The current study used the Cohen (1988) guidelines to determine the strength of the relationship as follows:

Weak relationship (r = .10 to .29): a correlation coefficient in this range suggests a weak or minimal relationship between the variables. The variables are somewhat related, but the relationship is not substantial. Moderate Relationship (r = .30 to .49): a correlation coefficient in this range indicates a moderate or medium strength of association between the variables. The variables are moderately related, and the relationship is more noticeable and meaningful than a weak relationship. Finally, strong relationship (r = .50 to 1.00): a correlation coefficient in this range reflects a strong or high-strength association between the variables. The variables are strongly related, and the relationship is robust and substantial.

In this program of study, Pearson's product-moment correlation coefficient (Pearson *r*) was used to measure associations between continuous variables. The relationship between two variables measured on ordinal scales were examined using the Spearman rank-order (r_s) coefficient. An associated p-value<0.05 was considered statistically significant.

Qualitative data analysis

I undertook a thematic analysis to interpret the qualitative data, which is described as "...a method for identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). Thematic analysis is commonly used in qualitative research and is a valuable tool that provides rich and detailed data (Braun & Clarke, 2006). One of the

advantages of this method is flexibility in addition to theoretical freedom (Braun & Clarke, 2006). The flexibility of this analysis extends beyond just the theoretical domain to research questions, sample sizes, data collection methods, and approaches to meaning generation. It enables the researcher to identify patterns within and across the data, particularly those related to the experiences, opinions, and behaviours of the participants (Clarke & Braun, 2017). Another advantage of the thematic analysis is its simplicity, making it easy to learn and apply. This is because it does not necessitate the use of theory to guide the analysis, thereby enabling researchers to adopt a purely inductive approach (Kiger & Varpio, 2020). Additionally, there are various published descriptions and examples of this method available (e.g. Braun & Clarke, 2006; Braun & Clarke, 2021; Kiger & Varpio, 2020), which makes it more accessible to novice researchers (Kiger & Varpio, 2020). Despite its simplicity, it is a powerful method that empowers researchers to summarise, emphasise significant aspects of, and interpret a diverse range of data sets (Kiger & Varpio, 2020).

When conducting the thematic analysis, I summarised and identified the themes of the interview data following Braun and Clarke's (2006) guidelines. First, prior of developing the initial codes the transcripts were read and reread to get familiar with the data. Then, similar codes were arranged under possible themes. After that, a review of the themes was conducted to check if the themes worked in relation to the codes and a thematic map was created. Finally, ongoing analysis of the data was conducted to generate a clear definition of each theme by continuously reviewing and refining the thematic analysis to ensure it accurately reflects the data and captures its complexity.

Establishing trustworthiness in qualitative research

The reliability of qualitative research has been a subject of debate for a long time. Positivists have argued that objective measures cannot be applied in the same way as in quantitative

research (Shenton, 2004). Therefore, qualitative research is often criticised for lacking scientific rigour and being viewed as a "soft" science (Cope, 2014). In response to criticisms about the quality of qualitative research, Lincoln and Guba (1985) proposed four criteria - credibility, dependability, confirmability, and transferability - which have been widely accepted by qualitative researchers as a means of improving the rigour and credibility of their research (Connelly, 2016; Polit & Beck, 2017). These criteria focus on aspects that should be considered during the design phase to demonstrate how the study design can ensure robustness and credibility of the data and their interpretation (Marshall & Rossman, 2011). For this study, all four criteria were followed to ensure the trustworthiness of the research. Table 1. highlights the strategies of each component that was utilised to ensure the trustworthiness of this research.

Table 1. Definitions and Strategies of Trustworthiness

Criteria	Credibility	Dependability	Confirmability	Transferability
Definitions	Credibility refers to the degree to which the data can be considered accurate and trustworthy (Polit & Beck, 2017).	Dependability refers to the consistency and quality of data across different situations and periods (Polit & Beck, 2017).	Confirmability pertains to the degree of objectivity or neutrality of both the data and its interpretation (Polit & Beck, 2017).	Transferability refers to the degree to which qualitative research findings can be applied to other contexts or populations (Polit & Beck, 2017).
Strategies	Peer debriefing Member checks	Audit trail Triangulation	Triangulation Reflexivity	Audit trail

Source: strategies were adopted from Guba (1981)

Peer debriefing includes discussing emergent findings with others to ensure that the analysis is grounded in the data (Marshall & Rossman, 2011). This debriefing helps to understand any

weaknesses and control biases in the analysis process, leading to a more accurate and reliable outcome (Haq et al., 2023). In this research, a strategy was implemented where weekly meetings were held with the supervisory team to discuss data collection, analysis, and result interpretation. These discussions were based on the team's extensive knowledge and experience of qualitative research, and their recommendations helped to improve the overall quality of the research.

Triangulation is a strategy that involves gathering data from various sources and using multiple methods and theoretical lenses to understand the research question (Marshall & Rossman, 2011). This method can help to reduce the possibility of biases that may arise from using a single method, thereby increasing confidence in any interpretations made (Fielding & Fielding, 1986; Maxwell, 1992; Onwuegbuzie & Leech, 2007). By utilising different data sources and methods, triangulation can lead to a more in-depth, honest, and comprehensive understanding of the subject matter (CohenMiller et al., 2022). In this study, I applied both qualitative and quantitative methods to compare data which helped to enhance the credibility of the research (Hesse-Biber, 2010).

Member checking is a process where the transcripts of participants' interviews or final reports are shared with them to ensure accuracy (Creswell & Creswell, 2018; Gray, 2014). In this research, I conducted a member checking strategy whereby I shared the interview transcripts with the participants, giving them the opportunity to review and provide additional clarifications if needed.

Audit trial. This strategy involves the collecting of materials and documentation about the research as it goes along, which, when presented allow others to understand how the research took place and the conclusions reached (Polit & Beck, 2017). It is useful for those who want to replicate the study or understand the transferability of results to new settings. In this study,

I conducted an audit trail by providing detailed notes on the process of the research and data collection, and then describing this within the thesis and publications.

Reflexivity is an essential practice in qualitative research that involves consistently examining and assessing how the researcher's personal experiences may have influenced the various stages of the research process. It requires a continual process of self-reflection and self-evaluation (Dowling, 2006; Olmos-Vega et al., 2023). In my study, I kept a reflexive journal to document any decisions and preconceived ideas I had about the study. To ensure that my biases did not influence the findings, I provided quotations to support the findings (Hanson et al., 2019), as presented in Chapter 5. I also discussed the different phases of the project development, data collection and analysis with my supervisory team to get their perspective on my own conclusions.

Purposive sampling is a method commonly used in qualitative studies. It is defined as "selecting units (e.g., individuals, groups of individuals, institutions) based on specific purposes associated with answering a research study's questions" (Teddlie & Yu, 2007, p. 77). This approach aims to gather a broad range of information from key informants (Guba, 1981) who possess significant knowledge of the phenomenon being investigated and provide comprehensive findings (Anney, 2014). In this study, I utilised purposive sampling techniques to select participants in the study, as detailed in Chapter 5.

Conclusion

This chapter has highlighted the methods used in this research. This research undertook a multi-methods approach, including a systematic review of relevant literature and mixed methods data collection, including qualitative and quantitative methods, to gain a better understanding of the nature of patient-centred practice from the different perspectives of patients and healthcare providers in Saudi Arabia. In the following chapters, the major

findings of the four studies will be presented. The first study is the systematic review. The following two studies involved a mixed methods approach. In the second study, qualitative research was conducted using semi-structured interviews to gain rich information from the participants about their experiences. This was teamed with quantitative research using an online questionnaire to assess patient perception of patient-centred care. The final study involved quantitative research investigating healthcare providers' perceptions of patient-centred care. The detailed methods for each study are included within the individual papers structured as journal articles.

CHAPTER 4

PATIENT-CENTERED CARE IN THE MIDDLE EAST AND NORTH AFRICAN REGION: A SYSTEMATIC LITERATURE REVIEW

Reeham Ahmed Alkhaibari[1,2], Jennifer Smith-Merry[3]*, Rowena Forsyth [4]and Gianina Marie Raymundo[1]

[1] Sydney School of Health Sciences, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW, Australia

[2] Nursing Department, College of Applied Medical Sciences, Taif University, Taif, Saudi Arabia

[3] Centre for Disability Research and Policy, Sydney School of Health Sciences, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW, Australia

[4] Cyberpsychology Research Group, Biomedical Informatics and Digital Health Theme, School of Medical Sciences, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW, Australia

*Corresponding author: Jennifer Smith-Merry, PhD
Email: jennifer.smith-merry@sydney.edu.au
Telephone: +61 2 9351 9060
Sydney School of Health Sciences, The University of Sydney
Susan Wakil Health Building, Western Avenue, Camperdown, NSW, 2006, Australia

Authorship attribution statement

The systematic review presented in this chapter was accepted and published in the *BMC Health Services Research Journal* as [*Alkhaibari, R. A., Smith-Merry, J., Forsyth, R., & Raymundo, G. M.. (2023). Patient-centered care in the Middle East and North African region: a systematic literature review. BMC Health Services Research, 23(1). https://doi.org/10.1186/s12913-023-09132-0]*. I co-designed the study with my supervisory team (J. Smith-Merry and R. Forsyth), searched databases, co-screened with other co-authors, co-extracted the data and co-analysed the data, and wrote the drafts of the manuscript.

Name Reeham Ahmed Alkhaibari

Signed_____

Date_____

As the supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statement above is correct. In addition, as the corresponding author of this manuscript, I approve of including this manuscript in this thesis.

Name Pro Jennifer Smith-Merry

Signed_____

Date_____

BMC Health Services Research

RESEARCH

Open Access

Patient-centered care in the Middle East and North African region: a systematic literature review

Reeham Ahmed Alkhaibari[1,2], Jennifer Smith-Merry[3*], Rowena Forsyth[4] and Gianina Marie Raymundo[1]

Abstract

Background The need for patient centered care (PCC) and its subsequent implementation has gained policy maker attention worldwide. Despite the evidence showing the benefits and the challenges associated with practicing PCC in western countries there has been no comprehensive review of the literature on PCC practice in the Middle East and North African (MENA) region, yet there is good reason to think that the practices of PCC in these regions would be different.

Objectives This paper summarizes the existing research on the practice of PCC in the MENA region and uses this analysis to consider the key elements of a PCC definition based on MENA cultural contexts.

Methods Five electronic databases were searched (EMBASE, Cochrane, Medline, CINAHL and Scopus) using the search terms: patient OR person OR client OR consumer AND centered OR centred AND care. The MENA countries included were Bahrain, Iran, Iraq, Jordan, Kuwait, Lebanon, Oman, Palestine, Israel, Qatar, Saudi Arabia, Syria, United Arab Emirates, Yemen, Algeria, Egypt, Libya, Morocco, Tunisia, Djibouti, Pakistan, Sudan, and Turkey. Identified papers were imported to Covidence where they were independently reviewed against the inclusion criteria by two authors. The following data were extracted for each paper: author, year, location (i.e., country), objectives, methodology, study population, and results as they related to patient centred care.

Result The electronic search identified 3582 potentially relevant studies. Fifty articles met the inclusion criteria. Across all papers five themes were identified: 1) patient centered care principles; 2) patient and physician perceptions of PCC; 3) facilitators of PCC; 4) implementation and impact of PCC; and 5) barriers to PCC.

Conclusion The preliminary findings suggest that the concept of PCC is practiced and supported to a limited extent in the MENA region, and that the implementation of PCC might be impacted by the cultural contexts of the region. Our review therefore highlights the importance of establishing patient-centered care definitions that clearly incorporate cultural practices in the MENA region. The elements and impact of culture in the MENA region should be investigated in future research.

Keywords Patient-centered care, Middle East, North Africa, Systematic review

*Correspondence:
Jennifer Smith-Merry
jennifer.smith-merry@sydney.edu.au
[1] Sydney School of Health Sciences, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW, Australia
[2] Nursing Department, College of Applied Medical Sciences, Taif University, Taif, Saudi Arabia
[3] Centre for Disability Research and Policy, Sydney School of Health Sciences, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW, Australia
[4] Cyberpsychology Research Group, Biomedical Informatics and Digital Health Theme, School of Medical Sciences, Faculty of Medicine and Health, The University of Sydney, Camperdown, NSW, Australia

Background

Patient centered care

Patient centered care (PCC) was introduced as a concept in the 1970s [1.], however it did not gain popularity until the United States-based Institute of Medicine (IOM) declared it as one of six dimensions necessary to achieve quality of care alongside safety, timeliness, effectiveness, efficiency, and equity [2.] Globally, however, there is no agreed definition of PCC in the literature [3.]. For instance, the Institute for Patient and Family Centered Care (IPFCC) provides a broad definition, defining PCC as "the approach to planning, delivering, and evaluating healthcare that is based on a partnership between health care providers, patients, and families" [4.] while on the other hand, Epstein & Street's [5.] definition focuses more on the interpersonal interactions of the healthcare encounter, describing it as an approach to treating patients with respect, recognising their preferences, engaging and involving them, and providing them with knowledge about their illness, care and treatment. Both definitions emphasise a need to establish a therapeutic relationship between health providers and patients in order to collaboratively achieve desired outcomes. Delaney [6.] states that PCC aims to create collaborative rapport and takes a comprehensive approach to meeting and acknowledging patients' values, increasing their participation and including them in decision-making. Patient involvement in care is also seen to be encapsulated by the phrase "nothing about me, without me" [7. , 8.]. As indicated by the name of the Institute for Patient and Family Centred Care, discussed above, another form of PCC is family centered care (FCC). The FCC model is based on the same fundamental aspects as PCC, but instead of focusing solely on the patient, it views patients and their family members as the care clients [9. , 10.].

Evidence suggests that PCC can lead to better outcomes including increased patient and staff satisfaction, reduction in medical errors, enhanced employee recruitment, increased employee retention, improved health status and reduced unnecessary tests and referrals [11. –17.]. The Picker Institute has established eight concepts of patient-centered care: prompt access to care; efficient treatment; quality care and adaptive transparency; patient and family involvement; comprehensible health care knowledge and support, mutual decision-making and respect for patient preferences; emotional support, empathy and respect, and awareness of physical and environmental needs [18. , 19.]. These concepts consider PCC at all stages of the patient's journey and their care environment.

The shift to PCC was part of an approach to health care based on patients' rights and aligned with the World Health Organisation (WHO) International Declarations of Geneva and Alma Ata [20. , 21.]. The rationale for adopting this approach was the global shift in health patterns from infectious diseases to chronic diseases, which increased demand for health care, and fears that the healthcare system might become overwhelmed when meeting these demands [22.]. A PCC approach views patients as the core of the healthcare system and part of the solution to improving the quality of care and, therefore, its effectiveness [23. , 24.]. An adoption of PCC, it was argued, would prioritise patients' rights in decision making, make care more targeted and motivate patients to take control and become experts in managing their conditions [25.]. Collaboration and relationship building between health providers and patients is key to the adoption of PCC. The elements of this collaborative relationship are explained in Carman's [24.] 'Framework for Patient and Family Engagement in Health and Health Care'. This framework points to a relationship where health providers' and patients' values, experiences, and perspectives in disease prevention, diagnosis and treatment are combined and enacted through providing clear information, communication, establishing goals, and participating in decision making, to proactively manage health. This relationship builds open communication to ensure that patients understand the risks and benefits associated with their health choices [24.].

The health care system and PCC in the Middle East and North Africa region

According to Webair [26.] middle eastern countries have had a long history of practicing the principles behind PCC as the provision of health care has been influenced by the principles of Islam since the medieval period. For instance, medieval Islamic medical practice involved treating patients without discrimination related to gender and identified ethics as a prerequisite for health provider practice. This resulted in high quality care provision, however in the present time, the PCC performance of middle eastern countries has been considered poor compared to other western countries [26.]. This poor performance may result from a wide range of factors, including changes to disease patterns, population growth and the increased demand on health services, cultural factors, lack of financial resources, administrative and organisational reasons, the inaccessibility of medical treatments and healthcare services due to poverty, and in some countries, instability from war [27. –29.].

In 2000, the World Health Organization (WHO) attempted to rank the health system performance of 191 countries based on five indicators including population health, health inequality, health system responsiveness to population needs, distribution of this responsiveness, and fairness in financing [30.].

Many Middle East and North Africa (MENA) countries were among the top 30 best performing health systems including, Oman, Saudi Arabia, the United Arab Emirates, and Morocco but others were poorly rated including Pakistan, Sudan, and Djibouti [30.]. Most countries in the MENA region have a split healthcare system with public and private funding of service delivery [27.] and comply with the Alma- Ata Declaration of 1978 to provide 'Health for All' [28. , 31.]. However, there is disparity in the quality of healthcare among these countries especially in rates of government funding [27.]. For example, oil rich countries such as Saudi Arabia [32.] can allocate oil revenue to improve health care, provide health care programs [28. , 33.], and universal access and affordable care [28.]. These all improve patients' access to and utilisation of the health system and therefore improve the quality of care [28.]. On the other hand, in low-income countries in the MENA region, such as Pakistan [34.], the health system remains in a fragile state due to factors which include lack of resources, poor structural management, lack of equity, gender insensitivity, and inaccessible and unaffordable health services [35.]. Moreover, currently, four countries in the MENA region—Syria, Iraq, Libya, and Yemen—are in a state of war[36.]. War and conflict affect health system quality [37.] due to the destruction of health infrastructure, a shortage of health care providers, and lack of medical equipment and medicines [38. –40.]. These factors can have varying degrees of impact on genders and communities [29.]. Therefore, while health systems in the MENA region need to adopt PCC methods to improve care delivery and governance by informing patient and provider education and policies [41.], they are not starting from an even base, and PCC needs to be implemented with an understanding of broader system development and characteristics. Webair [26.] also points out that the current published literature in the MENA region applies a western definition of PCC with the absence of a definition of PCC reflecting the culture of the region which includes a stronger emphasis on family and religion. These barriers are key features that must be considered when understanding how to improve the implementation of PCC in MENA countries.

This literature shows that there are possible structural and cultural limitations on the adoption of PCC in the MENA region but we lack a clear understanding of the factors impacting PCC implementation. There is also a necessity for establishing a definition of PCC based on the culture of the region which incorporates the particular circumstances impacting the implementation of PCC. The purpose of this review is to start to address these limitations by documenting the current published literature on PCC in the MENA region and to use this analysis to consider the essential elements of a MENA focused definition of PCC.

Method

A systematic literature review was performed of the published literature on patient centred care in the Middle East and North Africa. Systematic review described by Petticrew and Roberts [42.], p., 15) as "a method of critically appraising, summarising, and attempting to reconcile the evidence". This method is beneficial because it seeks to summarize published research that has been done in a certain field of study, provide an overview of the research field, highlight areas where research has been conducted, and identify knowledge gaps. This approach also allows us to take from this literature the key elements of PCC as practiced in the MENA region. For the purposes of this research, we define PCC in relation to the eight principles of PCC articulated by the Picker Institute, discussed earlier [19. , 43.]. We followed the scoping review process suggested by Peters et al. [44.] to conduct this review.

RA is an academic researcher who has spent much of her life living and working in Saudi Arabia. JSM, RF and GR are academic researchers with experience of Australia and other international health systems research contexts.

Literature search

A search was carried out in relevant electronic databases (EMBASE, Cochrane, Medline, CINAHL and Scopus) for studies that focus on patient-centered care in the MENA region and were published up to January 2021. The following terms were developed with the assistance of the university librarian to identify publications associated with patient-centred care: patient OR person OR client OR consumer AND centered OR centred AND care. The MENA countries of Bahrain, Iran, Iraq, Jordan, Kuwait, Lebanon, Oman, Palestine, Israel, Qatar, Saudi Arabia, Syria, United Arab Emirates, Yemen, Algeria, Egypt, Libya, Morocco, Tunisia, Djibouti, Pakistan, Sudan, and Turkey were used as keywords combined with the terms above in order to limit findings to the MENA region. Iran and Turkey were included in the study as they are sometimes included in the definition of the MENA region and share cultural and religious characteristics in common with the other countries [45. –47.]. Results imported from the databases were stored in the reference manager software EndNote and then imported to the systematic review software Covidence where duplicates were removed, and remaining papers screened for inclusion.

Study selection

The inclusion criteria were: 1) studies focusing on patient-centered care; 2) studies published in English and/or Arabic (the two languages spoken by the research team); 3) studies published in peer-reviewed journals; 4) studies that sampled participants (including patients, family members, health providers, and nursing and medical students 5) any study design that utilized qualitative, quantitative, or mixed methods approaches to data collection; and 6) studies published in the MENA counties. In addition, studies reported family centered care were also included in the review. Two reviewers (RA and GR) independently scanned the titles and abstracts to assess the relevance of the studies in relation to the inclusion criteria. Studies that potentially met the inclusion criteria were retrieved for full text screening. Any disagreement between reviewers was resolved by discussion between the reviewers, bringing in a third person (JSM) where necessary. Studies were excluded if they did not focus on PCC, were not conducted in the MENA region, included no data from participants, were conducted in languages other than Arabic or English, where full articles were not accessible, or were other types of papers (including reviews, systematic reviews, commentary, editorials, protocols, opinion pieces and conference papers).

Data extraction

The data were extracted and recorded into a spreadsheet in MS Excel from the Covidence software. Collected data recorded were the author, year, location (i.e., country), objectives, methodology, the study population, and findings of each study. The main themes across the papers were identified through an open coding scheme, with five categories created based on these key themes: patient-centered care principles; patient and physician perceptions of PCC; facilitators of PCC; implementation and impact of PCC; and barriers to PCC.

Results

Description of the literature

The database search initially resulted in the identification of 3582 articles (Fig. 1). Fifty articles met the inclusion criteria and were included in the review. Of the 50 articles, 29 used quantitative methods, 2 used mixed methods and 19 used qualitative methods. Studies were conducted in Iran (13), Israel (7), Saudi Arabia (6), Jordan (5), Pakistan (4), United Arab Emirates (2), Kuwait (1), Oman (1), Qatar (1), Turkey (1), Egypt (1) and Palestine (1). The seven remaining studies reported comparative data from multiple countries in the Middle East. Data were generated using a wide range of methodologies from qualitative interview designs, qualitative focus group designs, mixed qualitative methods studies, cross sectional surveys, quasi-experimental, randomized designs, non-experimental design, and mixed designs. Details of these studies are provided in Table 1. The sample sizes used ranged from 9 to 829 participants, with the smaller samples from qualitative studies and the largest sample from a multisite database study. The sample populations included health providers (20), patients and health providers (11), patients and family members (14), medical and nursing students (4), clinical and non-clinical staff (1), and academic and clinical experts (1).

Patient centered care principles

The key elements of PCC identified in the studies were: treating patients as an individual [67. , 70. , 89.] having empathy towards their conditions, advocating on their behalf and providing care with flexibility to meet patients' needs, incorporating patients' expectations and preferences [70. , 72. , 78. , 89.]. Papers also highlighted attentiveness to patient needs, including physical, religious, and social needs [70. , 72. , 89.]. Other key areas were health professionals' competency and expertise in protecting patients from harm, reducing hospitalization and costs of care [67. , 70. , 72.], complying with patients' rights [70. , 72.], effective communication [67. , 72. , 78. , 89.], and empowerment of patients through providing education [67.].

Patient and health provider perceptions of PCC

Several studies showed that patients and their relatives had a positive attitude toward patient involvement in care [52. , 59. , 62. , 80.]. Schattner et al. [92.] added that patients like to be informed about their health and participate in shared discussions and decision making about the care they receive. Dormohammadi, Asghari & Rashidian's [68.] study of hospitalized and ambulatory patients in Iran noted that patients prioritized health professional competence and positive attitudes. However, in the study by Joolaee et al. [78.], which focused on Iranian patients and their companions' experiences with caring relationships with health professionals, patients prioritized health professional positive behaviour and emotional support over competence.

There were variations regarding patients' and health providers' perspectives on the way in which patient-centered care was practiced. For instance, Yasein et al. [95.] wrote about patient and physician perspectives on patient-centeredness and communication skills in Jordan. The study found that patients rated many aspects of patient-centeredness and communication skills lower than junior doctors. Another study conducted in Israeli IVF units found that there were differences between the perceptions of patients and providers regarding the provision of the different aspects of PCC and the extent

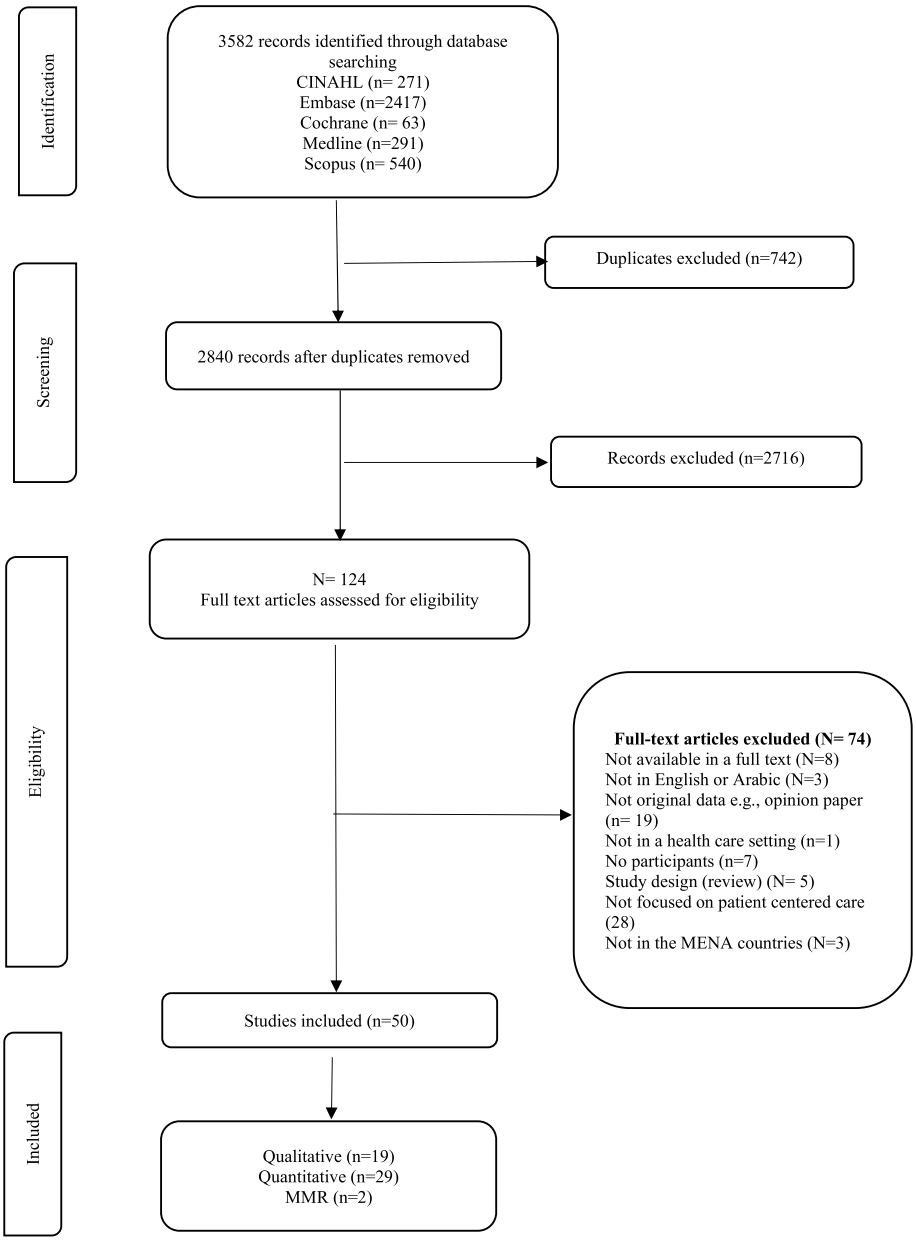

Fig. 1 Flow PRISMA diagram for search and selection process

to which each dimension of patient-centred care was applied. Dimensions assessed were for example, emotional support, respect for patient values and needs and provision of information and explanation of the 10 dimensions introduced by Picker Institute. Patient scores were lower than those of providers except for continuity of treatment and professional competence [83.]. This variation was also noticed in the practice of FCC. Several studies explored health provider perceptions of FCC. Cross-national differences in the perception of FCC were identified among healthcare providers in the United States, Australia, Turkey, and Saudi Arabia[54. , 73.]. A study by Alabdulaziz et al. [55.] investigated FCC in Saudi Arabia from the paediatric nurse perspective which showed that nurses acknowledge the significance of family-centered care elements however they find it difficult to apply this model in their daily practice. Overall, however, this variation in attitudes to PCC between patients and practitioners and across studies shows that there is no clear understanding of PCC common within the practices reported in the existing literature and, in relation to

Table 1 Summary of studies included in the review updated

Author and year	Country	Aim	Participant type	Study design and methods
Abdelhadi and Drach-Zahavy, 2012 [48.]	Israel	To test a model that suggests that the ward's climate of service facilitates nurses' patient-centred care behaviours through its effect on nurse work engagement	Nurses	Cross-sectional multi-level (nurses within wards) design
Abdel-Tawab and Roter, 2002 [49.]	Egypt	To examine the feasibility, acceptability, and effectiveness of client centered models of communication in 31 family planning clinics in Egypt	Physicians and clients requesting family planning methods	Quantitative interviews and questionnaire
Abdulhadi et al., 2007 [50.]	Oman	To explore the perceptions of type 2 diabetes patients regarding medical encounters and quality of interactions with their primary healthcare providers	Diabetic patients	Qualitative: Explorative study using Focus group
Ahmad et al.,2015 [51.]	Pakistan	To assess the leaning of medical students towards either a doctor-centred or a patient-centred care, and to explore the effects of personal attributes on care such as gender, academic year, etc	Medical student	Cross-sectional
Akkafi et al., 2019 [52.]	Iran	This study measured the attitudes of patients' family and personal caregivers (FPCs) and psychiatrists toward patient-centred care	Patients' FPCs and psychiatrists	Descriptive questionnaire-based study
Akturan et al., 2016 [53.]	Turkey	To investigate the effect of the BATHE therapeutic interview technique on the empowerment of diabetes mellitus patients in primary care	Diabetic patients	A cluster randomised controlled study
Alabdulaziz and Cruz, 2020 [54.]	Saudi Arabia	To explore the perceptions of nursing students toward family-centered care in Saudi Arabia	Undergraduate nursing students	Cross-sectional survey method
Alabdulaziz et al., 2017 [55.]	Saudi Arabia	To explore family-centred care in the Saudi context from the perspectives of paediatric nurses	Paediatric nurses	Mixed method sequential exploratory design
Alameddine et al., 2020 [56.]	Dubai	To explore the perceptions of physicians in regard to SDM in a large private hospital network in Dubai, United Arab Emirates	Health care providers	Cross sectional
Albougami et al., 2019 [57.]	Saudi Arabia	To examine the perceptions of expatriate nurses in Saudi Arabia regarding the relationship between cultural competence and patient-centred care	Expatriate nurses	Cross-sectional descriptive correlational survey

Table 1 (continued)

Author and year	Country	Aim	Participant type	Study design and methods
Alhalal et al., 2020 [58.]	Saudi Arabia	To assess the predictors of patient-centred care provision among nurses working in an acute care setting	Nurses	A cross-sectional predictive design
AlHaqwi et al., 2016 [59.]	Saudi Arabia	To determine the perceptions of patients on whether they receive sufficient information about their medical problems, their preferences to obtain information, and factors that may influence their preferences	Patients attending the primary health center during the study	Cross-sectional, questionnaire-based study
Aljaffary et al., 2020 [60.]	Saudi Arabia	To measure patient perceptions of shared decision-making practices during clinical encounters in Saudi Arabia	Patients and physician	Cross sectional
Al-Momani, 2010 [61.]	Jordan	To assess the satisfaction of mothers with paediatric health care at the Paediatric Unit (PU) of Paediatric and Maternity Hospital, Al- Mafraq, Jordan	Mothers at a Paediatric Unit	A descriptive/ correlation survey
Alshahrani et al., 2018 [62.]	Saudi Arabia and Australia	To explore the nature of relatives' involvement in the care of patients in acute medical settings in Australia and Saudi Arabia and to explore the perceptions, attitudes, and experiences of nurses	Female patients, their relatives, and nurses	Qualitative: Ethnography (Observation and interview)
Aminaie et al., 2019 [63.]	Iran	To explore the perception of barriers to decision making in Iranian patients with cancer regarding their care	Cancer patients	Qualitative: Incorporated individualized in depth and semi structured interview
Baig et al., 2020 [64.]	Pakistan	To explore significant facilitators and barriers to effective SDM as perceived by endocrinologists	Endocrinologists	Qualitative: In depth interview
Bentwich et al., 2018 [65.]	Israel	To explore whether normalization coping mechanisms exist among formal caregivers, reveal differences in its application among cross-cultural caregivers, and examine how coping mechanisms may related to implementing PCC for people with disability	Caregivers consisted of nurses, nurses' aides, occupational therapists, and physiotherapists	Qualitative
Bentwich et al., 2019 [66.]	Israel	To explore caregivers' verbal patterns for potential links between respect for the personhood of patients with dementia and caregiver use of figurative language	Caregivers three groups: Arabs, immigrants from the former Soviet Union and Jews born in Israel	Qualitative: using a discourse analysis of semi-structured interviews

Table 1 (continued)

Author and year	Country	Aim	Participant type	Study design and methods
Cheraghi et al., 2017 [67.]	Iran	To explore the process of providing patient-centred care in critical care units	Nurses, patients, and physician	Qualitative: used a grounded theory method semi structured interview
Dormohammadi et al., 2010 [68.]	Iran	To identify the most important expectations that patients have about their physicians	Hospitalized and ambulatory patients	Quantitative
Drach-Zahavy, 2009 [69.]	Israel	To assess the moderating effect of care orientation on the relationship of PCC to nurses' physical and mental health	Registered Nurses	Cross sectional study
Esmaeili et al., 2014 [70. , 71.]	Iran	To explore nurses' attitudes and experiences towards the barriers to achieving patient centred care in the critical care setting	Nurses working in intensive care units	Qualitative: In depth semi-structured interview
Esmaeili et al., 2014 [70. , 71.]	Iran	To explore the perception of nurses working in critical care units about patient-centred care, which is a crucial factor in attaining quality in nursing care	Nurses in critical care	A qualitative exploratory study using semi structured interview
Esmaeili et al., 2016 [72.]	Iran	To explore cardiac patients' perceptions of patient-centred care	Cardiac patients	Qualitative: Semi structured interview
Feeg et al., 2016 [73.]	United States, Australia, and Turkey	To describe and compare how healthcare providers from three countries with varied cultural and healthcare systems perceive the concept of FCC by measuring attitudes, and to develop a psychometrically sound measure that would reflect "family-centredness."	Providers working in paediatrics	multi-site comparative nonexperimental design
Ghaffari et al., 2020 [74.]	Iran	To determine the predictive values of patient-centred communication and patient characteristics on body image perception in postmastectomy patients	Surgically treated breast cancer patients admitted to the oncology departments of two hospitals in Iran	Predictive correlational study
Ghiyasvandian et al., 2018 [75.]	Iran	To explore therapeutic communication between patients and nursing students in the Iranian context through the perception of nursing students, nursing instructors, and patients	Nursing students, nursing instructor, and patients	Qualitative: In depth semi structured interview

Table 1 (continued)

Author and year	Country	Aim	Participant type	Study design and methods
Hayajneh et al., 2014 [76.]	Jordan	To describe the impact on professional caregiver burden of adopting person-centred care approaches for people with Alzheimer's disease	Professional caregivers	A qualitative descriptive phenomenological approach using semi-structured interviews
Hijazi et al., 2018 [77.]	Jordan	To examine the impact of applying quality management practices on patient centeredness within the context of health care accreditation and to explore the differences in the views of various health care workers regarding attributes affecting patient-centred care	Clinical/nonclinical hospital staff	A multiple-case study design
Joolaee et al., 2010 [78.]	Iran	To describe how Iranian patients and their companions explain their lived experiences with caring relationships in a central teaching hospital in Tehran, Iran	Patients and their companions	phenomenological approach was used and semi-structured interviews
Khullar and Coughlan, 2018 [79.]	Kuwait	To understand the types of narratives and treatment approaches that may contribute to inadequate service delivery	Individuals providing mental health services	Qualitative: using open-ended, semi-structured interviews
Lipovetski & Cojocaru, 2020 [80.]	Israel	To shed the light on the integration of caregiver- patient perspectives regarding decision-making processes, and the barriers and facilitators to their implementation in chronic-care practices in Israel	Patients with colorectal cancer and Oncologists	Mixed method Explanatory sequential design
Mahboub et al.,2018 [81.]	Dubai	To review current patient-centred practices for outpatients in both private clinics and public hospitals in Dubai	Patients had appointments in various outpatient departments (OPD) including medical, surgical, and general	Independent survey consisting of self-administered questionnaires
Manchaiah et al., 2014 [82.]	Portugal, India, and Iran	To examine and compare audiologists' preferences for patient-centredness in Portugal, India, and Iran	Audiologists	Cross sectional
Medina-Artom and Adashi, 2020 [83.]	Israel	To compare provider and patient perceptions of the extent to which care in Israeli IVF units is patient centred	Providers and patients	Quantitative using questionnaire
Mohamed et al., 2013 [84.]	Qatar	To assess the effectiveness of a culturally sensitive, structured education programme (CSSEP) on biomedical knowledge, attitudes, and practice measures among Arabs with type two diabetes	Patients with type II diabetes	A randomized controlled trial

Table 1 (continued)

Author and year	Country	Aim	Participant type	Study design and methods
Mole et al., 2016 [85.]	UK, Egypt, and India	To characterise understandings of 'good communication' in future doctors from medical schools in three contextually contrasting continents and test the hypothesis that there would be a lack of global consensus on what constitutes 'good communication'	Students in the clinical years of training (Years 3–6) who had personal experience with doctor–patient interactions	Qualitative: A mixed method using first focus groups and then interviews
Obeidat and Lally, 2018 [86.]	Jordan	To determine Jordanian physicians' perceived barriers and facilitators to patient participation in treatment decision-making	Physician	Quantitative: A cross sectional exploratory survey design
Rahman et al., 2019 [87.]	Pakistan	To examine the perspectives of 18 health care providers (nurses, consultant doctors, residents, radiologists, and physiotherapists) and 18 patients regarding best practices for patient-centred care in a free private hospital in Pakistan, to understand congruence between provider and patient perspectives	Patients and providers	Qualitative: Focused group interview
Rasha et al., 2009 [88.]	Saudi Arabia and US	To use the Communication, Curriculum, and Culture Survey (C3) to perform a pilot cross-cultural comparison of the patient-centredness of the hidden curriculum between a Saudi medical school and 9 U.S. medical schools	Senior Saudi medical students in their (6^{th}) last year	Quantitative
Rassouli et al., 2020 [89.]	Iran	To examine nurses' perceptions of the components of patient-centred care and its delivery	Nurses	Qualitative descriptive research using face to face semi structured and filed note interview
Rehman eta l., 2017 [90.]	Pakistan	To determine health care professionals' views on patient centricity, quality improvement and advancement required for life satisfaction in the health care sector	HCPs working in tertiary care hospital and after non solo clinic	Descriptive cross sectional
Sadati et al., 2016 [91.]	Iran	To explore the nature of doctor-patient interaction (DPI) in one educational hospital in Iran, according to the views of patients and their relative	Patients and their relatives	Qualitative: using the Carspecken's critical ethnography
Schattner et al., 2006 [92.]	Israel	To determine patient priorities in medical care	Hospitalized and ambulatory patients	Quantitative

Table 1 (continued)

Author and year	Country	Aim	Participant type	Study design and methods
Sultan et al., 2018 [93.]	Palestine	To investigates the provision of PCC among hospital doctors in the developing and politically unstable country of Palestine	Doctors	Descriptive, cross-sectional research
Topaz et al., 2020 [94.]	Israel and US	To understand the extent to which current health information technology (HIT) systems are supportive of PCC and how PCC should be supported by HIT in the future	Academic and clinical experts (Physician, Nurse, Human factors analysis/ human computer interaction experts. Other (socio-technical domain & social work)	A qualitative descriptive method interview
Yasein et al., 2017 [95.]	Jordan	To evaluate patient-centredness and communication skills from the patients' point of view and that of the physicians' point of view and compares the two outcomes	Patients and residents	Quantitative: A cross sectional study
Zisman-Ilani et al., 2020 [96.]	Israel, Jordan, and US	To understand the beliefs, perceptions, and practices related to shared decision making (SDM) and patient-centred care (PCC) of physicians in Israel, Jordan, and the United States	Physicians	Quantitative: using a web-based survey
Zolfaghari et al., 2015 [97.]	Iran	To study the effect of two educational methods (family-centred and patient-centred) on some complications that occur during haemodialysis	Patients	Clinical trial of quasi-experimental type

the Picker Institute definition, we can see that PCC is not fully implemented in the MENA region.

Facilitators of PCC

Factors influencing the practice of PCC were related to patient gender [59. , 60.] and the broader sociodemographic characteristics of physicians [49. , 51. , 58. , 93.], patient support networks [80. , 86. , 87.], patient-provider communication [64. –66. , 75. , 76. , 85.] and practitioner work environment [48. , 69. , 71. , 98.].

Two studies showed that patient gender was significantly associated with their preference to be informed of treatment plans and participate in decision making where women were more likely to be involved than men [59. , 60.]. However, this was not a universal finding, with Lipotevski and Cojocaru's [80.] study of patients with colorectal cancer and oncologists in Israel showing no association between preferences towards PCC and gender. This shows that the impact of gender on PCC may reflect the practice environment or prevailing social context of the country in which PCC is being implemented.

Practitioner demographic, education and practice context impacted on PCC uptake. Ahmad et al. [51.] investigated the relationship between demographic characteristics and the attitude of undergraduate medical students in the pre-clinical years and in clinical years towards PCC in Pakistan and found that foreign students studying in private medical schools were more in favour of PCC compared to local students. Physician age was also a factor, with Abdel-Tawab and Roter's [49.] study of a family planning program in Egypt suggesting that young physicians prefer to work in a patient-centered way. However, Alhalal et al. [58.] found that older providers were better at showing empathy, communicating effectively, responding to patients' needs, and sharing decisions with patients. Sultan et al. [93.] suggest that a broad range of demographic and educational factors influence physician views of the importance of PCC components. Relevant factors were practitioners' job title, age, marital status, and private hospital context, along with familiarity with PCC.

Several factors influenced health providers decisions to practice PCC. This included the availability of evidence, health professionals' values, environment or context-related factors, such as cultural beliefs [56.]. Involving clinical and non-clinical staff in service accreditation processes was also a significant factor in delivering PCC in health organization settings [77.].

For patients, PCC was facilitated by receiving emotional support from family and others [80.], family involvement in care more generally [87.] and patients bringing someone with them during a consultation [86.]. Several studies investigated patients' experience of PCC within health services in different settings, including family planning clinics [49.], private clinics, public hospitals [81.], and paediatric units [61.]. Factors contributing to patient satisfaction were positive talk [49.], timely services and appointments, and provision of clear explanations regarding the patients' medical conditions [81.].

With regard to facilitating factors associated with the work environment, Esmaeili et al.'s [70.] study of nurses working in critical care in Iran noted that nurses reported that organizational recognition of staff shortages, providing guidelines, support to staff and the presence of PCC role models in the workplace were facilitators of PCC. One study investigated the perceptions of expatriate nurses in Saudi Arabia concerning the relationship between cultural competence and patient-centered care. It found that there was a positive association between cultural competency and providing individualized care [98.]. Abdelhadi and Drach-Zahavy [48.] suggest in their study of nurses in north Israel that establishing a better climate of service and work engagement would influence PCC provision by providing support, training, and incentives. Alhalal, Alrashidi & Alanazi [58.] suggest that high levels of structural empowerment and compassion, satisfaction and low burnout are important factors that influence the provision of PCC by staff. In another study by Drach-Zahavy [69.], nurse mental health improved when providing a high quality care and high PCC and declined when the opposite was true.

In addition to doctors' attitudes, the papers emphasised that effective communication skills, including empathic and therapeutic communication, are essential elements of successful PCC by health care providers [64.]. Two studies explored PCC in relation to the implementation of coping strategies and supportive language by cross cultural care givers of people with dementia. Results showed that Arab care givers used figurative language and coping strategies embedded in PCC approaches which viewed people with dementia as individuals with unique needs [65. , 66.]. Hayajneh et al. [76.] found that empathetic relationships by staff with patients with Alzheimer's overrides stresses and allows implementation of effective coping strategies which reduce the burden of caring for people with Alzheimer's. Ghiyasvandian et al. [75.] found that therapeutic communication assists health providers to provide PCC that aligns with patient needs. It establishes trust with patients through asking permission before providing care, guides conversations to patient needs, is responsive to their needs, and provides personalised communication influenced by religious, cultural, and professional values. Utilizing patient-centered communication strategies was significantly associated with better health outcomes [74.]. Rahman et al. [87.] found several key physician behaviours that facilitate

PCC including positive attitudes, allocating time for consultation, cultural responsiveness and the use of simple language and props to demonstrate procedures. However, a study conducted to compare perceptions of 'good communication' across medical schools in different sociocultural contexts found there was variation in what is considered to be good communication [85.]. This variation was associated with different views on the role of family, gender, and emotional expression across the study sites. One study compared PCC in the hidden curriculum in a Saudi medical college with nine US medical colleges. The results suggested that the hidden curriculum in Saudi schools is more physician than patient-centered [88.].

Implementation and impact of PCC

The impact of different PCC strategies on patients and physicians was a significant theme in the identified papers, however because of the disparate nature of the topics and settings, the papers approached this theme from a variety of angles. Two studies utilised the BATHE interview technique (Background, Affect, Troubling, Handling, and Empathy) and empowerment educational sessions to empower diabetic patients [53. , 84.]. The studies used HbA1c, BMI and patient empowerment scores as outcomes and found mixed results, with one finding a reduction in HbA1c and BMI values as a result of the intervention (-0.55 mmol/L, $P<0.0001$; -1.70 kg, $P=0.001$) [84.] and another finding no significant differences [53.]. However, other improvements were found such as knowledge of diabetes, attitude towards diabetes, and in practice such as patient compliance with the treatment [84.] and empowering diabetic patients [53.]. Another study based in Iran assessed the effect of FCC and PCC on complications during haemodialysis [97.]. Findings suggested that family-centred education led to improved treatment outcomes including reducing haemodialysis complications and depression and increasing satisfaction and self-care.

Barriers to PCC

Papers reported barriers to PCC as arising from 1) the individual patient and their support environment, 2) the health professional and 3) the organizational environment. Individual patient barriers included patients' low levels of education, low health literacy and lack of motivation to take an active role in their health [50. , 64. , 80.]. Low literacy was identified as a barrier to managing health care by both patients and health care providers. Abdulhadi et al. [50.] argued, in an Oman-based study, that patients reported that they could not interact with health care providers due to their low levels of education. They found that patients with low levels of education hesitated to interact with their health care providers as they feared that their interference would negatively affect their relationship with the healthcare provider [50.]. Two other studies cited lack of knowledge or low health literacy and self-efficacy as barriers to PCC [80. , 96.]. However, another study reported physicians' perceptions that there was no relationship between patient level of education and participation in decision making [64.].

Papers reported that patient centred care is related to patient beliefs about their illnesses or the nature of health care interactions. For example, patients do not acknowledge the seriousness of their illnesses or have expectations of healthcare encounters which focus on treatment rather than consultation and this affects the patient's interactions with the health care professional [80. , 86. , 96.]. Two studies noted patients' understanding of the health care relationship as a barrier to PCC. This resulted from medical dominance and patient views of health care provider authority [63. , 80.]. Medical dominance was defined by Iranian cancer patients as the provision of inadequate information to patients, perceived authoritarian behaviours in physicians, as well viewing patients as objects for financial gain [63.].These factors resulted in the inability to discuss physician decisions [63.]. For patients this led to fear and despair about the lack of alternative treatment options.

A number of papers reported the impact of culture on patient centered care. Aminaie et al. [63.] noted barriers to PCC that were associated with patient ethnicity, faith, and language. Their Iranian study explored how cancer patients perceive barriers to participation in decision-making and found that patients preferred to receive care in a familiar health care organization so they would feel comfortable in communicating with their health care professional to seek more information. Key to this was a concern that the health care professional would not dismiss their faith [63.]. Meanwhile, in a study by Alabdulaziz et al. [55.], nurses working in Saudi Arabia with different languages, religions and cultures to their patients, was viewed as a barrier to involving patients and their families in decision-making. Baig et al. [64.] reported that health providers hold respected positions in Pakistani culture and were encouraged to make decisions without involving patients.

The role of family members and caretakers as a potential barrier to PCC in health care interactions was reported in several studies. One study investigating Jordanian physicians' views of the barriers and facilitators to patient involvement in decision making found that 65.5% of physicians reported involving the family in decision making as a barrier to PCC as families would interfere and make decision on behalf of the patient [86.]. Baig

et al. [64.] noted that family involvement in Pakistan is two-edged as involving family can help in managing patients' conditions however it can also be counterproductive if handled incorrectly.

Many studies reported health care professional behaviours as a barrier to PCC [63. , 80.]. These included dismissing patient and family concerns, negative attitudes toward PCC, a lack of eye contact when interacting with patients, poor sharing of information and delays in care provision [50. , 63. , 80.]. Patients also noted a lack of privacy during interactions with the health care provider, poor communication as the health professional was busy taking notes, poor encouragement of patient involvement, and poor provision of information or explanation of patient conditions [50. , 63. , 64.].

A lack of professional motivation on the part of health practitioners has also been described as a barrier impacting the implementation of PCC. This was associated with their lack of interest in the profession, low salaries, staff shortages, not receiving financial incentives, workload burden and dissatisfaction [64. , 71.]. A lack of collaboration between the healthcare team members [71. , 87.] as a result of poor communication between physicians and nurses due to gender sensitivity was also reported as a barrier to PCC [87.].

Limited understanding of the concept of PCC was cited as a barrier to the implementation of PCC in two studies [80. , 96.]. Zisman-IIani et al. [96.] found that only 40% of Jordanian physicians and 71% of Israeli physicians understood the PCC concept. Studies also commented on healthcare provider lack of expertise and competence regarding patient conditions [50.]. Abdulhadi et al. [50.] noted that patient perceptions of health care providers' lack of knowledge of diabetes was due to the short consultation time, infrequent physical examinations, and a misguided belief that diabetes is not a serious health condition.

Various organizational barriers towards PCC were reported across studies. The lack of time resulting from high workloads and patient loads led to practitioners being less able to share information with patients [55. , 64. , 71. , 80. , 86.]. Other factors which inhibited PCC included a lack of organisational and managerial support, scarce resources and facilities, administrative blockages, lack of staff, and limited time to establish rapport and negotiate care [55. , 63.]. Two studies described long waiting times as a barrier to PCC [50. , 87.] which was as a result of bed shortages, high patient loads, lack of free services and a lack of referral practices in the health care system [87.]. A lack of training and guidelines, and resources to support PCC was also a significant organizational barrier [55. , 71. , 80. , 96.].

Discussion

This review systematically assessed 50 articles which had a significant focus on patient-centered care practice in the MENA region. The included studies focused primarily on patient-centered care principles; patient and physician perceptions of PCC; facilitators of PCC; implementation and impact of PCC; and barriers to PCC. Numerous barriers and facilitators were reported across the studies. While facilitators related to all groups, facilitators were most commonly reported to be related to physician attitudes and practice, there is an ongoing need for literature that explores the facilitators of PCC related to patients and organizations, in order to offer a more multi-layered approach to improving PCC.

The cultural context of MENA and PCC

Our findings suggest that culture plays a significant role in influencing patient provider relationships and therefore the extent to which PCC is practiced. Patient-provider interactions are rooted within prevailing cultural and religious norms and influenced by time and setting [99. , 100.]. This profoundly influences patient attitudes, beliefs, and health-related practices [101.]. Social behaviour and practices in much of the MENA region are governed by cultural norms and religion [64.] whereby community, family, and religion play a significant role in decision-making [87. , 102.]. Following the dimensions of culture introduced by Hofstede, Hofstede, and Minkov ([103.], p., 103–104), Middle Eastern countries are characterised by dependent collectivism where decisions related to health are made collectively by family members [50. , 104.]. With respect to the dimension of power distance, defined as the degree to which less powerful individuals expect and accept an unequal power distribution ([103.], p., 61), this was evident in a country like Pakistan where health providers, such as doctors and elderly family members, held an authoritative position. Consequently, in such societies doctors are viewed as the "instruments of God" and "paternal figures" and therefore have the power to make decisions, which impacts on the practice of PCC [64. , 86. , 100.]. Accordingly, family systems and the position of authority that a doctor holds forms the basis for medical decision making in many MENA countries [105.].

We also observed in our review that family involvement was viewed as both a barrier and a facilitator to PCC by both patients and health providers [62. , 64. , 86.]. Family members in countries in the middle east play a protective role for their hospitalised members by providing spiritual and financial support. On the other hand, a family might interfere with patient treatment plans [50. , 86.]. Consequently, family members may be the ones to make the decisions for the patient or patients may delegate their

family to participate in the decision-making process [64. , 86. , 104. , 105.]. The role of family in understanding PCC in the MENA region is therefore essential to a developing contextual definition of PCC.

Islam is the most prevalent religion in the MENA region [106.]. In this religion, the importance of hygiene, diet, and exercise is taught, and people are encouraged to practice healthy behaviours. However, the provision of health care might also be hindered by certain beliefs, including the patient preferences of the provider's gender [107.] and gender may therefore play a key role in patient-provider interactions which impacts on the practice of PCC [108.]. In societies where gender separation exists it is common for women to choose a female provider over a male provider and involve a male family member in decision making [104. , 107. , 109. , 110.]. Failing to provide health care services in accordance with gender-based, religious and cultural needs is therefore considered a barrier to care and will impact on PCC. This finding is supported by several studies conducted with Muslim women in western countries, such as the United States and Australia, which have shown that women seek care if it is aligned with their religious and cultural values [101. , 111. –113.]. These findings show that gender is a key part of the cultural operationalisation of PCC in the MENA region and must be considered within the practice of PCC.

PCC practice facilitators and barriers

The key facilitators of PCC found in this review were 1) the establishment of a therapeutic relationship between the health provider and patient 2) practices which treated the patient as a whole person, 3) respect, including of patient preferences and values, 4) effective communication, and 5) provider behaviour. Treating the patient as a whole and treating them with respect and empathy were key aspects of provider behaviour, which together with other facilitators, such as effective communication, worked to facilitate PCC. These findings are supported in a narrative review of patient provider communication. King & Hoppe [114.] suggested six functions as the 'best practice' during patient-provider consultation: 1) establishing a relationship, 2) obtaining information, 3) sharing information, 4) decision making, 5) promoting disease and treatment behaviours, and 6) the ability to respond to emotions.

This review also confirms previous research on PCC barriers conducted in different settings. A scoping review of studies based in Australia, Canada, Netherlands, Norway, Sweden, and the United States involving migrants and refugee women found that the barriers to PCC were determined by patient health and language literacy levels, health provider behaviours and knowledge (i.e., lack of knowledge about culture and religion), and organizational practices (i.e., lack of language services) [115.]. Another systematic review of 23 qualitative studies involving children and young people in mental health services found that a lack of specialist knowledge, poor communication, and scarce resources hinder PCC implementation [116.]. In addition to those practices already mentioned, these can be overcome by equipping health providers with confidence and knowledge through explicit training in PCC [116.] and by modelling PCC behaviours and in workplaces that explicitly espouse key PCC values through providing specialized training courses to improve for instance communication skills [50. , 90. , 95.]. Salary incentives and promotion opportunities could also be offered to motivate health providers to enhance their qualifications and improve their abilities to provide patient-centered care [98.]. Creating organizational programs that emphasize decentralization, in addition to providing access to information, support, resources, and opportunity would enable PCC [58.]. In addition, integrating the concept of patient and family-centered care within the educational curriculum [54. , 64.] and providing students with opportunities to acquire the necessary skills needed for clinical practice [61.] would further enable the adoption of PCC. Notably, establishing patient-centered care relies on changes associated with both patients and physicians therefore there is a need to improve health literacy which would support PCC practice where patients' behaviour would change from passive to more involved in decision making [52. , 67.].

PCC for the MENA region

This paper has used existing research to map out the dimensions of current practices in patient centred care in the MENA region. Most studies did not employ relevant PCC frameworks or engage with the broader PCC literature. There are several existing frameworks that describe the dimensions of PCC. For example, Scholl et al. [117.] have proposed an integrative model that can be used in different healthcare settings and health care education to design a curriculum focusing on PCC. Mead and Bower [118.] also proposed dimensions that determine the effectiveness of patient-provider interactions. However, none of these frameworks were developed with reference to the MENA region or have been explored in relation to the region. In order to consider the scope of research practice on PCC in the MENA region we compared our findings with the eight dimensions of PCC introduced by the Picker Institute and the Commonwealth Fund (see background section) [19. , 43.]. According to our findings, there had been little focused research on the dimensions of coordination of care, emotional support, physical

comfort, and continuity of care in the MENA region. These dimensions are significant indicators of patients' perception of the quality of care and there is therefore a need to focus on these dimensions in future research.

As described above there are considerable local contextual factors that mean that the model of PCC operating in the MENA region may be different to that conceptualised elsewhere. We have highlighted the key factor of culture and, in particular, the impacts of the role of the family in health care, the impact of practitioner social standing, and gender as being key to understanding the practice of PCC in the region. These should all be key to a revised conceptual definition of PCC in the MENA region.

Conclusion

This systematic review is the first review conducted in the MENA region. From this discussion we can conclude that the health care system in the MENA is influenced by culture that impacts on the interactions between providers and patients, places a greater emphasis on family rather than individual patient involvement in care and emphasizes collectivism over individualism. Future research is needed to explore this further and investigate the association of culture and patient willingness to participate in decision making and PCC.

Our review indicates that there is support for adopting PCC in the MENA region, but that the practice of PCC is limited. This was acknowledged in multiple studies [52. , 83. , 91. , 95.] in different care settings. We therefore conclude that considerable effort is still needed to ensure that health care in the MENA region is patient centered. The transition to patient-centredness requires a focus on patients, healthcare providers and organisations. However, we have seen that within the broad context of PCC, the patient's preference to participate in care varies depending on their cultural background.

This review showed that there is lack of a common definition of PCC in this region. The literature also showed that definitions must be adaptive to the local MENA context and should incorporate an understanding of culture which incorporates a focus on family involvement, the impact of the health practitioner's social standing, and gender. This understanding of PCC in the MENA region, including this developing definitional work, must be discussed in further research.

Acknowledgements
Not applicable.

Authors' contributions
RAA led the project design, data collection, analysis and initial manuscript draft. RAA and GR carried out the independent review of articles with assistance from JSM who reviewed all results and decided on inclusion where conflicts arose. JSM and RF supervised the project and, collaborated on all aspects of writing the manuscript. All authors contributed to and approved the final manuscript.

Funding
The lead author is supported by a PhD scholarship from Taif university.

Availability of data and materials
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Received: 6 May 2022 Accepted: 31 January 2023
Published online: 09 February 2023

References

1. Balint E. The possibilities of patient-centered medicine. J R Coll Gen Pract. 1969;17(82):269–76.
2. Io M, CoQoHCi A. Iom, National Academy of S: Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, D.C: National Academies Press; 2001.
3. Jo Delaney L. Patient-centred care as an approach to improving health care in Australia. Collegian. 2018;25(1):119–23.
4. Patient and family centered care [https://www.ipfcc.org/about/pfcc.html].
5. Epstein RMMD, Street RLP. The values and value of patient-centered care. Ann Fam Med. 2011;9(2):100–3.
6. Jo Delaney L. Patient-centred care as an approach to improving health care in Australia. Collegian. 2018;25(1):119–23 (Royal College of Nursing, Australia).
7. Backman WD, Levine SA, Wenger NK, Harold JG. Shared decision-making for older adults with cardiovascular disease. Clinical cardiology (Mahwah, NJ). 2020;43(2):196–204.
8. Delbanco T, Berwick DM, Boufford JI, Edgman L, Ollenschläger G, Plamping D, Rockefeller RG. Healthcare in a land called peoplepower: nothing about me without me. Health Expect. 2001;4(3):144–50.
9. Kokorelias KM, Gignac MAM, Naglie G, Cameron JI. Towards a universal model of family centered care: a scoping review. BMC Health Serv Res. 2019;19(1):564.
10. Gilmer MJ. Pediatric palliative care. Crit Care Nurs Clin. 2002;14(2):207–14.
11. Charmel PA, Frampton SB. Building the business case for patient-centered care. Healthc Financ Manage. 2008;62(3):80–5.
12. Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. J Gen Intern Med. 2012;27(5):520–6.
13. Griffin SJ, Kinmonth A-L, Veltman MWM, Gillard S, Grant J, Stewart M. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. Ann Fam Med. 2004;2(6):595–608.
14. Peimani M, Nasli-Esfahani E, Sadeghi R. Patients' perceptions of patient–provider communication and diabetes care: a systematic review of quantitative and qualitative studies. Chronic Illn. 2020;16(1):3–22.
15. Rao JK, Anderson LA, Inui TS, Frankel RM. Communication interventions make a difference in conversations between physicians and patients: a systematic review of the evidence. Med Care. 2007;45(4):340–9.

16. Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, Jordan J. The impact of patient-centered care on outcomes. J Fam Pract. 2000;49(9):796–804.
17. Ulin K, Malm D, Nygårdh A. What is known about the benefits of patient-centered care in patients with heart failure. Curr Heart Fail Rep. 2015;12(6):350–9.
18. Flitcroft K, Brennan M, Spillane A. Principles of patient-centred care and barriers to their implementation: a case study of breast reconstruction in Australia. Support Care Cancer. 2020;28(4):1963–81.
19. Principles of Person Centred Care [https://www.picker.org/about-us/picker-principles-of-person-centred-care/].
20. World Health Organization. Declaration of Alma-Ata: International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978.
21. Roberti Di Sarsina P, Tassinari M. Person-centred healthcare and medicine paradigm: it's time to clarify. EPMA J. 2015;6(1):11.
22. World Health Organization. People-centred health care : a policy framework. Manila: WHO Regional Office for the Western Pacific; 2007.
23. Carman K. Implementation, engagement, and use: making health care more patient-centered, reliable, and safe. In: Plenary session remarks at: Agency for Healthcare Research and Quality 2012 Annual Conference. 2012. p. 2012.
24. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, Sweeney J. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health Aff. 2013;32(2):223–31.
25. Pulvirenti M, McMillan J, Lawn S. Empowerment, patient centred care and self-management. Health Expect. 2014;17(3):303–10.
26. Webair HH. Patient-centered care in the Middle East. In: Laher I, editor. Handbook of healthcare in the Arab World. 2020th ed. Cham: Springer International Publishing; 2020. p. 1–17.
27. Dent E, Toki D, Dupuis N, Marquis J, Suyeshkumar T, Benlamri M. Healthcare systems within the Middle East. Unive West Ont Med J. 2017;86(2):35–6.
28. Mate K, Deen N, McCall J, Bryan C. Review of health systems of the Middle East and North Africa Region. 2016. p. 347–56.
29. Kronfol NM. Access and barriers to health care delivery in Arab countries: a review. East Mediterr Health J. 2012;18(12):1239–46.
30. Tandon A, Murray CJ, Lauer JA, Evans DB. Measuring overall health system performance for 191 countries. Geneva: World Health Organization; 2000.
31. Shawky S. Primary health care in the Eastern Mediterranean Region: from Alma-Ata to Doha/Les soins de sante primaires dans la Region de la Mediterranee orientale: d'Alma-Ata a Doha. East Mediterr Health J. 2010;16(12):1285.
32. O'Sullivan A, Rey M-E, Mendez JG. Opportunities and challenges in the MENA region. Arab World Competitiveness Rep. 2011;2012:42–67.
33. Parkash J, Younis MZ, Ward W. Healthcare for the Ageing Populations of countries of Middle East and North Africa. Ageing Int. 2015;40(1):3–12.
34. Hassan A, Mahmood K, Bukhsh HA. Healthcare system of Pakistan. IJARP. 2017;1(4):170–3.
35. Kurji Z, Premani ZS, Mithani Y. Analysis of the health care system of Pakistan: lessons learnt and way forward. J Ayub Med Coll Abbottabad. 2016;28(3):601.
36. Dhaoui I. Healthcare system efficiency and its determinants: A two-stage Data Envelopment Analysis (DEA) from MENA countries. Working Paper 1320: Giza: Economic Research Forum (ERF); 2019.
37. Mowafi H. Conflict, displacement and health in the Middle East. Glob Public Health. 2011;6(5):472–87.
38. Al Faisal W, Al Saleh Y, Sen K. Syria: public health achievements and sanctions. The Lancet. 2012;379(9833):2241.
39. Kherallah M, Alahfez T, Sahloul Z, Eddin KD, Jamil G. Health care in Syria before and during the crisis. Avicenna J Med. 2012;2(3):51.
40. Sharara SL, Kanj SS. War and infectious diseases: challenges of the Syrian civil war. PLoS Pathog. 2014;10(11): e1004438.
41. Bombard Y, Baker GR, Orlando E, Fancott C, Bhatia P, Casalino S, Onate K, Denis J-L, Pomey M-P. Engaging patients to improve quality of care: a systematic review. Implement Sci. 2018;13(1):98–98.
42. Petticrew M, Roberts H. Why do we need systematic reviews? In: Systematic reviews in the social sciences. 2016. p. 1–26 edn.
43. Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: a systematic review of the literature. Med Care Res Rev. 2013;70(4):351–79.
44. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. JBI Evid Implement. 2015;13(3):141–6.
45. Bazm S, Bazm R, Sardari F. Growth of health literacy research activity in three Middle Eastern countries. BMJ Health Care Inform. 2019;26(1): e000027.
46. Chaabna K, Cheema S, Abraham A, Maisonneuve P, Lowenfels AB, Mamtani R. The state of population health research performance in the Middle East and North Africa: a meta-research study. Syst Rev. 2021;10(1):1–1.
47. Tiliouine H, Meziane M. The History of Well-Being in the Middle East and North Africa (MENA) In M Estes and R. Sirgy (eds) The Pursuit of Human Wellbeing. Cham: Springer International Publishing; 2017:523–63.
48. Abdelhadi N, Drach-Zahavy A. Promoting patient care: work engagement as a mediator between ward service climate and patient-centred care: promoting patient-centred care. J Adv Nurs. 2012;68(6):1276–87.
49. Abdel-Tawab N, Roter D. The relevance of client-centered communication to family planning settings in developing countries: lessons from the Egyptian experience. Soc Sci Med 1982. 2002;54(9):1357–68.
50. Abdulhadi N, Al Shafaee M, Freudenthal S, Ostenson C-G, Wahlström R. Patient-provider interaction from the perspectives of type 2 diabetes patients in Muscat, Oman: a qualitative study. BMC Health Serv Res. 2007;7(1):162–162.
51. Ahmad W, Krupat E, Asma Y, Fatima N-E, Attique R, Mahmood U, Waqas A. Attitudes of medical students in Lahore, Pakistan towards the doctor-patient relationship. PeerJ (San Francisco, CA). 2015;3:e1050–e1050.
52. Akkafi M, Sajadi HS, Sajadi ZS, Krupat E. Attitudes toward patient-centered care in the mental care services in Isfahan Iran. Community Ment Health J. 2019;55(3):548–52.
53. Akturan S, Kaya ÇA, Ünalan PC, Akman M. The effect of the BATHE interview technique on the empowerment of diabetic patients in primary care: a cluster randomised controlled study. Prim Care Diabetes. 2016;11(2):154–61.
54. Alabdulaziz H, Cruz JP. Perceptions of female Saudi undergraduate nursing students toward family-centered care. Nurse Educ Today. 2020;89:104421–104421.
55. Alabdulaziz H, Moss C, Copnell B. Paediatric nurses' perceptions and practices of family-centred care in Saudi hospitals: a mixed methods study. Int J Nurs Stud. 2017;69:66–77.
56. Alameddine M, AlGurg R, Otaki F, Alsheikh-Ali AA. Physicians' perspective on shared decision-making in Dubai: a cross-sectional study. Hum Resour Health. 2020;18(1):33–9.
57. Albougami AS, Alotaibi JS, Alsharari AF, Albagawi BS, Almazan J, Maniago J, EiRazkey J. Cultural competence and perception of patient-centered care among non-Muslim expatriate nurses in Saudi Arabia: A cross sectional study. Pak J Med Health Sci. 2019;13(2):933-9.
58. Alhalal E, Alrashidi LM, Alanazi AN. Predictors of patient-centered care provision among nurses in acute care setting. J Nurs Manag. 2020;28(6):1400–9.
59. AlHaqwi A, AlDrees T, AlRumayyan A, AlFarhan A, Badri M. Patient's desire and preference for provision of information toward greater involvement in shared care. Saudi J Med Med Sci. 2016;4(3):172–7.
60. Aljaffary A, Alhuseini M, Rayes SA, Alrawiai S, Hariri B, Alumran A. The OPTION scale: measuring patients' perceptions of shared decision-making in the kingdom of Saudi Arabia.(ORIGINAL RESEARCH). J Multidiscip Healthcare. 2020;13:1337–46.
61. Al-Momani M. Establishing family centred care in paediatric unit in Jordan: quality improvement. Singapore Nurs J. 2010;37(2):34–42.
62. Alshahrani S, Magarey J, Kitson A. Relatives' involvement in the care of patients in acute medical wards in two different countries—an ethnographic study. J Clin Nurs. 2018;27(11–12):2333–45.
63. Aminaie N, Mirlashari J, Lehto R, Lashkari M, Negarandeh R. Iranian cancer patients perceptions of barriers to participation in decision-making: potential impact on patient-centered care. Asia Pac J Oncol Nurs. 2019;6(4):372–80.
64. Baig AM, Humayaun A, Mehmood S, Akram MW, Raza SA, Shakoori T. Qualitative exploration of factors associated with shared

decision-making in diabetes management: a health care provider's perspective. Int J Qual Health Care. 2020;32(7):464–9.
65. Bentwich ME, Dickman N, Oberman A, Bokek-Cohen YA. "I treat him as a normal patient": unveiling the normalization coping strategy among formal caregivers of persons with dementia and its implications for person-centered care. J Transcult Nurs. 2018;29(5):420–8.
66. Bentwich ME. Bokek-Cohen Ya, Dickman N: How figurative language may be related to formal care-givers' person-centred approach toward their patients with dementia. Ageing Soc. 2019;39(12):2653–70.
67. Cheraghi MA, Esmaeili M, Salsali M. Seeking humanizing care in patient-centered care process: a grounded theory Study. Holist Nurs Pract. 2017;31(6):359–68.
68. Dormohammadi T, Asghari F, Rashidian A. What do patients expect from their physicians? Iran J Public Health. 2010;39(1):70–7.
69. Drach-Zahavy A. Patient-centred care and nurses' health: the role of nurses' caring orientation. J Adv Nurs. 2009;65(7):1463–74.
70. Esmaeili M, Cheraghi MA, Salsali M. Critical care nurses' understanding of the concept of patient-centered care in Iran: a qualitative study. Holist Nurs Pract. 2014;28(1):31–7.
71. Esmaeili M, Ali Cheraghi M, Salsali M. Barriers to patient-centered care: a thematic analysis study. Int J Nurs Knowl. 2014;25(1):2–8.
72. Esmaeili M, Cheraghi MA, Salsali M. Cardiac patients' perception of patient-centred care: a qualitative study. Nurs Crit Care. 2016;21(2):97–104.
73. Feeg VD, Paraszczuk AM, Çavuşoğlu H, Shields L, Pars H, Al Mamun A. How is family centered care perceived by healthcare providers from different countries? An international comparison study. J Pediatr Nurs. 2016;31(3):267–76.
74. Ghaffari F, Ghahramanian A, Zamanzadeh V, Onyeka TC, Davoodi A, Mazaheri E, Asghari-Jafarabadi M. Patient-centred communication for women with breast cancer: relation to body image perception. J Clin Nurs. 2020;29(23–24):4674–84.
75. Ghiyasvandian S, Abdolrahimi M, Zakerimoghadam M, Ebadi A. Therapeutic communication of Iranian nursing students: a qualitative study. Pertanika J Soc Sci Hum. 2018;26(3):1757–74.
76. Hayajneh FA, Shehadeh A. The impact of adopting person-centred care approach for people with Alzheimer's on professional caregivers' burden: an interventional study. Int J Nurs Pract. 2014;20(4):438–45.
77. Hijazi HH, Harvey HL, Alyahya MS, Alshraideh HA, Al abdi RM, Parahoo SK. The impact of applying quality management practices on patient centeredness in Jordanian Public Hospitals: results of predictive modeling. Inquiry (Chicago). 2018;55:46958018754739.
78. Joolaee S, Joolaei A, Tschudin V, Bahrani N, Nikbakht AN. Caring relationship: the core component of patients' rights practice as experienced by patients and their companions. J Med Ethics Hist Med. 2010;3:1.
79. Khullar N, Coughlan R. Person-centered versus disease-centered narratives among mental health providers in Kuwait: a critical and qualitative analysis of iatrogenesis and global medical discourse in action. Int J Ment Health. 2018;47(4):254–83.
80. Lipovetski O, Cojocaru D. Achieving patient-centered care with shared decision-making among colorectal cancer patients in Israel. Revista de cercetare şi intervenţie socială. 2020;70:250–64.
81. Mahboub B, Mawasi A, Ali S, Spina C. Patients' satisfaction as a dimension of quality: a survey on outpatients' care in Dubai. Int J Health Care Qual Assur. 2018;31(8):1030–43.
82. Manchaiah V, Gomersall PA, Tomé D, Ahmadi T, Krishna R. Audiologists' preferences for patient-centredness: a cross-sectional questionnaire study of cross-cultural differences and similarities among professionals in Portugal. India and Iran BMJ open. 2014;4(10):e005915–e005915.
83. Medina-Artom TR, Adashi EY. Patient-centered care in Israeli IVF units: divergent perceptions of patients and providers. Israel J Health Policy Res. 2020;9(1):1–39.
84. Mohamed H, Al-Lenjawi B, Amuna P, Zotor F, Elmahdi H. Culturally sensitive patient-centred educational programme for self-management of type 2 diabetes: a randomized controlled trial. Prim Care Diabetes. 2013;7(3):199–206.
85. Mole TB, Begum H, Cooper-Moss N, Wheelhouse R, MacKeith P, Sanders T, Wass V. Limits of "patient-centredness": valuing contextually specific communication patterns. Med Educ. 2016;50(3):359–69.
86. Obeidat R, Lally R. Jordanian physicians' perceived barriers and facilitators to patient participation in treatment decision-making: an exploratory study. Indian J Cancer. 2018;55(4):377–81.
87. Rahman R, Matthews EB, Ahmad A, Rizvi SM, Salama U, Samad L, Khan M. Perceptions of patient-centred care among providers and patients in the orthopaedic department of a tertiary care hospital in Karachi, Pakistan. J Eval Clin Pract. 2019;25(6):1160–8.
88. Rasha A-B, Benjamin B, Saad A-S, Samuel JS. Cross-cultural comparison of the patient-centeredness of the hidden curriculum between a Saudi Arabian and 9 US medical schools. Med Educ Online. 2009;14(1):19.
89. Rassouli M, Zamanzadeh V, Valizadeh L, Ghahramanian A, Asghari E. Limping along in implementing patient-centered care: qualitative study. Nurs Pract Today. 2020;7(3):217-225.
90. Rehman H, Ahmed Z, Hashmi F, Jamil K. Challenging status about patient centricity among health care profession in Pakistan. Rawal Med J. 2017;42(3):414–20.
91. Kalateh Sadati A, Bagheri Lankarani K, Hemmati S: Patients' description of unexpected interactions: a critical ethnography of the quality of doctor-patient interactions in one educational hospital in Shiraz, Iran. Shiraz E-Med J. 2016;17(7–8):e59931
92. Schattner A, Bronstein A, Jellin N. Information and shared decision-making are top patients' priorities. BMC Health Serv Res. 2006;6(1):21–21.
93. Sultan WIM, Sultan MIM, Crispim J. Palestinian doctors' views on patient-centered care in hospitals. BMC Health Serv Res. 2018;18(1):766–766.
94. Topaz M, Bar-Bachar O, Admi H, Denekamp Y, Zimlichman E. Patient-centered care via health information technology: a qualitative study with experts from Israel and the U.S. Inform Health Soc Care. 2020;45(3):217–28.
95. Yasein NA, Shakhatreh FM, Shroukh WA, Farah MS, Jaber RM. A Comparison between patients' and residents' perceptions of patient centeredness and communication skills among physicians working at Jordan University Hospital. Open Nurs. 2017;7(6):698–706.
96. Zisman-Ilani Y, Obeidat R, Fang L, Hsieh S, Berger Z. Shared decision making and patient-centered care in Israel, jordan, and the united states: exploratory and comparative survey study of physician perceptions. JMIR Form Res. 2020;4(8): e18223.
97. Zolfaghari M, Asgari P, Bahramnezhad F, AhmadiRad S, Haghani H. Comparison of two educational methods (family-centered and patient-centered) on hemodialysis: related complications. Iran J Nurs Midwifery Res. 2015;20(1):87–92.
98. Albougami A. The relationship between cultural competence levels and perceptions of patient-centered care among Filipino and Indian expatriate nurses working in the Saudi Arabian Healthcare Sector. In: ProQuest Dissertations Publishing. 2016.
99. Foucault M. The birth of the clinic: an archaeology of medical perception. London: Tavistock publications; 1973.
100. Matusitz J, Spear J. Doctor-patient communication styles: a comparison between the United States and three Asian countries. J Hum Behav Soc Environ. 2015;25(8):871–84.
101. Hasnain M, Connell KJ, Menon U, Tranmer PA. Patient-centered care for muslim women: provider and patient perspectives. J Womens Health. 2011;20(1):73–83.
102. Moazam F. Families, patients, and physicians in medical decisionmaking: a Pakistani perspective. Hastings Cent Rep. 2000;30(6):28.
103. Hofstede G, Hofstede GJ, Minkov M. Cultures and organizations : software of the mind : intercultural cooperation and its importance for survival, revised and expanded. 3rd ed. New York: McGraw-Hill; 2010.
104. Ezenkwele UA, Roodsari GS. Cultural competencies in emergency medicine: caring for Muslim-American patients from the Middle East. J Emerg Med. 2013;45(2):168–74.
105. Aslam F, Aftab O, Janjua NZ. Medical decision making: the family–doctor–patient triad. PLoS Med. 2005;2(6): e129.
106. Kabasakal H, Dastmalchian A, Karacay G, Bayraktar S. Leadership and culture in the MENA region: an analysis of the GLOBE project. J World Bus. 2012;47(4):519–29.
107. Odeh Yosef AR. Health beliefs, practice, and priorities for health care of Arab Muslims in the United States. J Transcult Nurs. 2008;19(3):284–91.
108. Dreachslin JL, Gilbert MJ, Malone B. Diversity and cultural competence in health care : a systems approach. New York: Wiley; 2012.

109. McLean M, Al Yahyaei F, Al Mansoori M, Al Ameri M, Al Ahbabi S, Bernsen R. Muslim Women's Physician Preference: Beyond Obstetrics and Gynecology. Health Care Women Int. 2012;33(9):849–76.
110. Padela AI, Del Pozo PR. Muslim patients and cross-gender interactions in medicine: an Islamic bioethical perspective. J Med Ethics. 2011;37(1):40–4.
111. Matin M, Lebaron S. Attitudes toward cervical cancer screening among Muslim women: a pilot study. Women Health. 2004;39(3):63–77.
112. Rajaram SS, Rashidi A. Asian-Islamic women and breast cancer screening: a socio-cultural analysis. Women Health. 1999;28(3):45–58.
113. Tsianakas V, Liamputtong P. What women from an Islamic background in Australia say about care in pregnancy and prenatal testing. Midwifery. 2002;18(1):25–34.
114. King A, Hoppe RB. "Best practice" for patient-centered communication: a narrative review. J Grad Med Educ. 2013;5(3):385–93.
115. Filler T, Jameel B, Gagliardi AR. Barriers and facilitators of patient centered care for immigrant and refugee women: a scoping review. BMC Public Health. 2020;20(1):1–1013.
116. Gondek D, Edbrooke-Childs J, Velikonja T, Chapman L, Saunders F, Hayes D, Wolpert M. Facilitators and barriers to person-centred care in child and young people mental health services: a systematic review. Clin Psychol Psychother. 2017;24(4):870–86.
117. Scholl I, Zill JM, Härter M, Dirmaier J. An integrative model of patient-centeredness - a systematic review and concept analysis. PLoS ONE. 2014;9(9):e107828–e107828.
118. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. Soc Sci Med. 2000;51(7):1087–110.

Publisher's Note

CHAPTER 5

"I AM NOT JUST A PLACE FOR IMPLEMENTATION. I SHOULD BE A PARTNER": A QUALITATIVE STUDY OF PATIENT PERCEPTIONS OF THEIR INVOLVEMENT IN CARE IN SAUDI ARABIA.

Reeham Ahmed Alkhaibari[1,2], Jennifer Smith-Merry[3] and Rowena Forsyth[4]

[1] Sydney School of Health Sciences, Faculty of Medicine and Health, The University of Sydney, NSW, Australia

[2] College of Nursing, Taif University, Taif, Saudi Arabia

[3] Centre for Disability Research and Policy, Sydney School of Health Sciences, Faculty of Medicine and Health, The University of Sydney, Sydney, NSW, Australia

[4] Cyberpsychology Research Group, Biomedical Informatics and Digital Health Theme, School of Medical Sciences, Faculty of Medicine and Health, The University of Sydney, Sydney, NSW, Australia

Corresponding author: Reeham Ahmed Alkhaibari
Email: ralk6229@uni.sydney.edu.au
Telephone: +61 451943042
Sydney School of Health Sciences, The University of Sydney
Susan Wakil Health Building, Western Avenue, Camperdown, NSW, 2006, Australia

Authorship attribution statement

The article presented in this chapter was accepted and published in the *BMC Health Services Research Journal* as [*Alkhaibari, R. A., Smith-Merry, J., & Forsyth, R.. (2023). "I am not just a place for implementation. I should be a partner": a qualitative study of patient-centered care from the perspective of diabetic patients in Saudi Arabia. BMC Health Services Research, 23(1). https://doi.org/10.1186/s12913-023-10391-0*]. I co-designed the study and co-analysed the data with my supervisory team (J. Smith-Merry and R. Forsyth) and wrote the drafts of the manuscript.

Name Reeham Ahmed Alkhaibari

Signed_____

Date _____

As the supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statement above is correct.

Name Pro Jennifer Smith-Merry

Signed_____

Date_____

BMC Health Services Research

RESEARCH Open Access

"I am not just a place for implementation. I should be a partner": a qualitative study of patient-centered care from the perspective of diabetic patients in Saudi Arabia

Reeham Ahmed Alkhaibari[1,2*], Jennifer Smith-Merry[3] and Rowena Forsyth[4]

Abstract

Introduction Patient involvement in care is a major component of high quality of care and is becoming recognized worldwide with many beneficial for improving patient outcomes. However, a little is known about patient involvement in the Middle East region and Saudi Arabia in particular.

Objectives To evaluate patients' perceptions of their involvement during their interactions with healthcare providers in Saudi Arabia.

Methods A qualitative exploratory study using semi structured interview was conducted from February 2022 to March 2022. Responses were transcribed and analyzed using a thematic analysis approach.

Results We conducted seven interviews with patients with diabetes ranging in age from 19 to 69 years old. We identified the following themes:1) patients' perceptions of their involvement in care, 2) barriers to patient involvement, 3) effective communication, 4) empathy, and 5) culture. We found that patients had minimal knowledge of patient involvement in care.

Conclusion There is a clear need to improve education and awareness of patient involvement in Saudi Arabia. By educating patients about the possibilities of patient involvement and explaining their role it will make it easier for patients to understand appropriate levels of involvement. In addition, there is a need to understand the patient-centred care culture in Saudi Arabia through establishing frameworks with the focus on culture and patient-centred healthcare delivery.

Keywords Patient involvement, Patient centered care, Saudi Arabia

*Correspondence:
Reeham Ahmed Alkhaibari
ralk6229@uni.sydney.edu.au
[1]Sydney School of Health Sciences, Faculty of Medicine and Health, The University of Sydney, NSW, Australia
[2] College of Nursing, Taif University, Taif, Saudi Arabia
[3]Centre for Disability Research and Policy, Sydney School of Health Sciences, Faculty of Medicine and Health, The University of Sydney, Sydney, NSW, Australia
[4]Cyberpsychology Research Group, Biomedical Informatics and Digital Health Theme, School of Medical Sciences, Faculty of Medicine and Health, The University of Sydney, Sydney, NSW, Australia

Introduction

Patient involvement in care is considered a central pillar of patient centered care (PCC) [1]. The United States-based Institute of Medicine (IOM) highlights PCC as one of the six core elements of achieving quality care along with safety, timeliness, effectiveness, efficiency, and equity [2]. Multiple studies have shown that patient involvement is associated with positive outcomes including improved patient knowledge and health status [3–8]. In order to achieve PCC, Corbett and Ennis [9] emphasized that health providers are required to shift away from the traditional paternalistic paradigm of care where practitioners know best and patients follow their advice unquestioningly. This paradigm shift enables patients to become more knowledgeable, involved, emancipated and therefore able to control and participate in their own healthcare. This shift requires establishing a relationship between patients and health providers that is based on negotiation and compromise until they reach an agreement to implement the best option of care [10]. Couët et al. [11] argue that patient involvement does not only rely on the healthcare provider and therefore it is unrealistic to consider that health providers alone hold the responsibility to involve patients; patients and communication practices also play a significant role. Engagement and interaction with providers represents the primary opportunity for patients to impact medical decisions and the course of treatment [12]. Patients can also enhance their comprehension of the medical process, particularly the rationale behind treatment and follow-up procedures [12]. PCC therefore relies on effort and interaction between patients and providers in the context of appropriate communication, where all need to work together to successfully implement PCC.

Involving patients in care

Internationally, there have been efforts to promote the philosophy of patient involvement in care. For example, the Picker Institute is a not-for-profit organization, located in the United States, that collaborates with patients, family, health providers and policymakers to improve patient experience in healthcare. It promotes an approach to patient experience based on the eight dimensions of PCC: prompt access to care; efficient treatment; quality care and adaptive transparency; patient and family involvement; comprehensible healthcare knowledge and support, mutual decision-making and respect for patient preferences; emotional support, empathy and respect, and awareness of physical and environmental needs [13]. These dimensions provide a guideline for healthcare organizations to implement and, when necessary, improve the delivery of PCC [14]. Another example is the Planetree model, utilized by health organizations worldwide [15]. Through patient and health worker feedback the Planetree model identifies PCC principles including providing compassionate care, establishing therapeutic partnership between patients, family members, and health providers through patient education and recognizing the significance of providing mental and spiritual support to patients [16, 17].

Research shows that there are a number of factors that influence patients' preferences regarding their involvement in care. A systematic review found that patients want to be engaged in their care [18] but that their preferences might differ based on their demographic and personal characteristics which include gender, health status, level of education and age [19–21]. For example, patients who are female, with better health, have higher levels of education and are younger are more likely to be actively involved in care, in contrast to patients with low socioeconomic status, who are severely ill, have low levels of education and are male [20, 22, 23].

Patient centred care in Saudi Arabia

The plethora of literature focusing on PCC is predominantly from western cultures with minimal research or literature focusing on Middle Eastern countries which means that there is limited understanding of whether and how PCC is practiced in the Middle East and what barriers and facilitators to that practice might be [24]. Existing literature focused on healthcare in the Middle East indicates that patients support their involvement in care [1, 25, 26] and there is a growing interest in PCC in the Middle East. However, there are still many obstacles to delivering PCC and integration of PCC in health systems in the Middle East region is lacking [24].

In Saudi Arabia, patient-centred practice of in some health organizations remains in its infancy due to existing health system priorities being centred on staffing and resources [27]. The global shift to PCC has led the Saudi government to propose transformational goals as part of its *Vision 2030* to improve healthcare, quality of life, healthcare organization and staff accountability to deliver care that is safe, effective, patient centred, timely, and equitable [27, 28].However, a study conducted in Saudi Arabia with hospitalized patients found that they were not aware of their rights to be fully informed of their medical condition and treatment plan [29].

Few studies have specifically explored PCC in Saudi Arabia from the patients' perspective. [1]. Existing studies that do focus on some aspects of patient perspectives have demonstrated that patients exhibit a preference for involvement in decision-making regarding their medical care [30, 31]. However, some patients still lean towards a paternalistic approach, where medical decisions are predominantly made by healthcare professionals [30]. Interventions to promote PCC culture to improve adherence to treatment plans and therefore better health outcomes

are recommended [31]. There is also a need to explore in depth patients' preferences to be involved in care to implement PCC more effectively in Saudi Arabia [30, 31]. This study addresses the deficit by employing qualitative interviews to explore patient experiences, to provide data for enhancing patient-centred care practices and implementing necessary improvements in Saudi Arabia.

To understand PCC practice we have chosen to focus on a patient group where people need to have ongoing interactions with healthcare providers as part of the management of their health needs. We focus on people living with diabetes as it is an illness that requires ongoing management and medical care, adoption of a healthy lifestyle, and regular health examinations, with interventions more successful with patient involvement in this care [32]. In Saudi Arabia, there are several challenges that affect the quality of diabetes care. These challenges can be characterized as patient factors (which include adherence, compliance, attitudes, beliefs, knowledge, financial resources, and co-morbidity) and healthcare providers factors (associated with their beliefs, attitudes, knowledge, interaction between health professionals and patients, and communication) [33]. People with diabetes may also face a serious range of complications which includes blindness, cardiovascular disease, and neuropathy which might lead to amputation [34] thus, they are often faced with treatment decisions that require urgency [35]. This means that they are already highly likely to have participated in decision making over the course of their condition, but also have to interact with a variety of health providers and can therefore reflect on their level of involvement more broadly [36, 37]. This exploratory study therefore aims to provide detailed experiential data related to the perspectives of people living with diabetes regarding their involvement in healthcare in Saudi Arabia. We examine patient perceptions of PCC to add to address gaps in existing literature related to patient attitudes towards PCC in the Middle Eastern region.

Methods

Study design

A qualitative exploratory study was conducted to assess patients' perceptions of their involvement during interactions with healthcare providers. The study aimed to achieve an in-depth understanding of the social reality of the research participants by exploring their personal experiences of their involvement in care and their experiences of their interactions with healthcare providers [38, 39]. This publication adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) [40].

Setting and participants

The setting of this study was the Diabetic Center at King Abdulaziz Specialist Hospital, one of the referral hospitals offering specialized services in Taif, Saudi Arabia. This hospital was chosen due to its strategic geographical location and patient demographic, as Taif is recognized for having a high prevalence of diabetes [41]. Inclusion criteria for participants were that they were at least 18 years of age, had been living with type 1 or type 2 diabetes mellitus, were currently receiving care at a diabetic center in Saudi Arabia, and could speak and understand Arabic, which is the main language used in Saudi Arabia. Purposive sampling was used as we sought to recruit participants from a range of ages and who had varying lengths of time living with diabetes. As this was an exploratory study, the aim was not for generalizability of findings but to include a study population who could provide in-depth content-rich data based on their experiences. As described by Malterud et al. [42] such a sample provides 'high informational power' and therefore lower sample sizes are acceptable for this type of analysis. Participants were initially recruited via a more general online questionnaire (reported elsewhere) focusing on patient provider interactions and perspectives related to PCC. This survey invitation was distributed using WhatsApp which is a common way of communicating with patients in this setting. At the end of this survey participants were asked if they wanted to participate in an interview. An email with the information statement and the consent form was sent to all participants who indicated their interest. Seven participants provided their consent and participated in an interview.

Ethical approval

The study protocol was approved by the Human Research Ethics Committee of the University of Sydney [2021/530] and from the Saudi Arabia Directorate of Health Affairs Taif Institutional Review Board [HAP-02-T-067 number 596]. Written consent was obtained from participants and all participants were informed that their participation was voluntary. All potentially identifying information was removed from the interview transcripts at the point of transcription and checked by members of the research team to assure that any quotations used in the paper did not inadvertently identify participants. Transcripts were checked by participants who could remove any data that they did not want included in the study.

Data collection

Semi structured telephone interviews were conducted between February 2022 and March 2022. The interview schedule contained open-ended questions related to patient experiences of their interactions with healthcare providers. An example of the questions asked in the interviews were "How do you define your role in the healthcare?" And "Do you prefer to be involved in making decisions regarding your healthcare? Why/why not?".

Probes were used to elicit more detailed responses when needed. Notes were taken during the interviews. The duration of the interviews ranged from 20 to 51 min, with an average of approximately 34 min. All interviews were conducted in Arabic by the lead researcher (RAA) who is fluent in Arabic and English. After the transcription was completed, all interviews were translated from Arabic into English by the lead author. The anonymized transcripts were reviewed by another native Arabic and English speaker to ensure the translation was accurate. The analysis was conducted on the English-language version of the transcripts, so the other authors could confirm the validity of the data and analysis process.

Researchers

RAA is a Saudi Arabian female PhD candidate and a lecturer at Taif University, with experience of the Saudi healthcare system, has received training in conducting qualitative research and did not know any of the seven interviewees in advance of the study. JSM is a female Professor with extensive experience in qualitative research and has conducted research previously in Saudi Arabia and other countries in the Middle East. RF is a female senior lecturer with extensive experience of in qualitative research.

Data analysis

As this was an exploratory study, where we were interested in the phenomenon of patient centred care from the perspective of patients, we conducted an inductive analysis of the data which aimed to draw out the key aspects of their experiences of care. In qualitative studies the validity of research is verified through the criteria of credibility, confirmability, transferability, and dependability [43]. We followed a credible, structured process of data analysis using the thematic analysis process proposed by Braun and Clarke [44] to identify, analyze, and report the patterns from the data. The transcripts were read several times for familiarization before initial codes were developed. After that, similar codes were grouped into potential themes. The next stage, review of the themes, was conducted to ensure that themes formed a coherent pattern. Once the themes were adequately identified we created a thematic map. Lastly, ongoing analysis was conducted to define the essence of each theme.

The lead author discussed and reviewed all steps of the analysis with other authors. To ensure the credibility of the findings we employed member checking with transcripts shared with participants for them to review and to add anything they wanted to clarify further. To enhance transferability, we provided background information about each of the participants. In addition, we documented an audit trail of all the processes of data collection and data analysis throughout the study to ensure confirmability. Dependability was ensured through using an interview schedule, audio recording and full transcription of the interviews. As this aimed to be an exploratory study utilizing Braun and Clark's [44] method of analysis saturation was not an aim of the data collection [45]. Instead we aimed to provide an insight into understandings of patient-centred care from the participants via in-depth interviews [38, 42]. The findings section below is ordered in relation to the main themes identified during the inductive coding process described above.

Table 1 Participants' demographic characteristics

Participants ID	Gender	Age	Highest qualification	Duration living with diabetes
P1	Male	40–54	Undergraduate degree and above	10 years and more
P2	Male	40–54	Undergraduate degree and above	10 years and more
P3	Female	18–39	Undergraduate degree and above	2–5 years
P4	Female	18–39	Undergraduate degree and above	10 years and more
P5	Male	55–64	Undergraduate degree and above	10 years and more
P6	Male	65–74	Undergraduate degree and above	10 years and more
P7	Female	18–39	Undergraduate degree and above	6–10 years

Findings

Participant demographics

Table 1 outlines the participant demographic characteristics. The study participants consisted of three females and four males, with three aged 18–39 and four aged over 40. Five participants reported they had been diagnosed with diabetes for more than 10 years with the other two ranging from 2 to 5 and 6–10 years since diagnosis. The majority of participants indicated that their highest level of qualification was a bachelor's degree.

Patients' responses

The study findings explore the experiences of the participants and how they viewed their involvement in decision making. The interviews were mutual interactions where both the lead researcher and the research participant were engaged in dialogue. A description of the participants' situations is provided below in order to provide context to their individual responses:

P1: Through the interview it was clear that P1 was irritated about how he had been treated by health providers and his voice was full of hope that his participation in this research would make a positive impact on patient involvement in care.

P2: This participant passionately demanded better care and was desperate to have a healthcare provider with full knowledge of his condition who would seek to obtain more information from him.

P3: During the interview P3 indicated her disappointment with her recent interaction with a healthcare provider who does not speak Arabic. However, she appeared to be more reluctant to express negative opinions about healthcare providers.

P4: This participant was upset and disappointed with her healthcare provider for ignoring her and preferring to interact with her parents rather than interacting with her. During the course of the interview her tone shifted as she started describing her favorite healthcare provider, who is a female, as the healthcare provider was the only one who would actively listen to her and allow her to express her thoughts.

P5: This participant's voice was calm and full of gratefulness. He positively recalled his healthcare provider's positive attitude when she connected him with other healthcare providers to keep following up on his other health issues. He was touched by this personalized approach. He hoped that a new generation of healthcare providers would participate positively to improve patient-provider relationships.

P6: In his interview P6 sounded conflicted or confused as he believes that there is no relationship between healthcare providers and patients, however later he explained the relationship should be based on what a patient needs and what the doctor has to offer. He was hesitant to express negative opinions especially when he was asked about the impact of gender roles.

P7: During the interview P7 sounded defeated because for a long time she had never experienced any involvement from her previous healthcare providers and therefore was hesitant to get involved in her care or share concerns with her provider. However, more recently her experience changed as she was assigned to a new healthcare provider who motivated her and encouraged her to voice her opinions. She prefers to have a friendship with healthcare providers as she believes it is the way to facilitate her interactions with them.

Table 2 Themes and categories from thematic analysis

Themes	Categories
Patients' perceptions of their involvement in care	Patient involvement
	Patient role in care
Barriers to patient involvement	Patient related barriers
	Health provider related barriers
	Environmental related barriers
Empathy	Patient empathy toward healthcare providers
Effective communication	Communication skills
	Health provider characteristics
Culture	Gender role
	Cultural norms

Qualitative themes

Participants shared their experiences of involvement in care and what they believe is their role in the healthcare system. We identified five key themes: patients' perceptions of their involvement in care, barriers to patient involvement, effective communication, empathy, and culture. Elements of these themes can be seen in Table 2 with each expanded on in turn within the text below.

Patient perception of their involvement in care

Patients displayed favorable views towards patient involvement with regard to their own health. For example, one participant stated: "I support it [patient involvement] in order to be a partner in the outcome" (P6). Participants varied however as to the extent to which they wanted to be involved in care. Participants commented on the importance of their own expertise of diabetes as the basis of their role for participating in decision making.

> *"I am the one who will practice the treatment. Therefore, the opinion of the patient should be taken in everything …. In my opinion I should be a partner in the treatment. I am not just a place for implementation. I should be a partner. I am the most knowledgeable person in my case, and I should have full information about the disease and the treatment plan and how it works. What is my role in achieving progress in it? … the patient should be a participant deciding on a treatment plan" (P1).*

> *"Because I am the patient … the doctor studied the disease, but he does not feel it. I mean, he did not live with it personally. I am the one who can describe my experience, and make a decision, this is for my benefit…I must interact with the doctor so that the decision going to be useful for me, not just that I have to comply with it." (P4).*

Other participants stated that they preferred to have a minimal role in their care and mostly rely on the healthcare providers' medical knowledge for decision making. Example comment was:

> *" Some decisions only the doctor can make…I follow his decision because he has experiences with people before me…I may express my opinion, but I respect the doctor's opinion" (P2).*

One participant was clear that she did not want to be involved in care and instead preferred to rely on

doctors' knowledge however, she wanted to be involved to improve her own lifestyle. She commented:

> *"My participation, I mean, I will not participate in general, I mean, almost the doctor knows everything, but some daily practices, some sleep regime, for example, I mean, I feel this thing belongs to me" (P3).*

Whilst some participants claimed that they supported the idea of patient involvement in care, when questioned about their roles or involvement in healthcare the interviewees demonstrated minimal knowledge of what would generally be associated with the key attributes of patient involvement in PCC, for example within the Planetree or Picker Institute models discussed earlier. For example, one participant stated:

> *"The patient's role is helping the doctor by complying with the treatments and following diets, as he [healthcare provider] says by exercising with the treatment… [the] patient must take care of himself. The most important thing is to follow the instructions that the doctor says" (P2).*

Another participant commented:

> *"I follow the things the health provider instructs for example, appointments, using treatment, adhering to the health provider's recommendations… the most important thing is to adhere to the things that the doctor has recommended." (P5).*

When asked about the role of healthcare providers, participants likewise stated that it was to "listen to the patient and asking questions" (P5) or to "diagnose patients and explain the treatment to the patient" (P6). The role of patients in these responses was more associated with complying with healthcare provider directions and treatment, which indicates a passive patient rather than an active one. Another participant addressed the absence of patient involvement practices in care in the healthcare system in Saudi Arabia, stating that the "… patient role is marginalized. The patient mostly doesn't have a role" (P1).

In summary, it appeared that most of the diabetic patients wanted to be involved in their care. However, for some, the way in which they articulated their role in care was to comply with healthcare provider instructions and be involved in adopting a healthier lifestyle. Hence, from these responses it appears that some participants were unaware of their role in care and therefore to the concept of patient involvement.

Barriers to patient involvement

Despite the support for patient involvement in care expressed by participants, they expressed several barriers when interacting with healthcare providers. These barriers were (i) patient related; (ii) healthcare provider related; or (iii) environment related.

Patient related barriers

Participants expressed that they were concerned about interacting with the healthcare providers. One participant commented:

> *"…I am a person; … I do not like to be ignored by anyone… my treatment plan was built by myself based on the doctor's words and the information I have, so I do not rely on his [healthcare provider] treatment plan. I just try to follow the tests and try to follow up on the sugar levels with them, so I consider it part of my treatment plan" (P1).*

One female participant also commented that she did not like to engage with the doctor during consultations but preferred to communicate with the healthcare provider through the diabetes educator.

> *"I am not the type to express …. I mean the doctor tells me what he has… that if he asked me, I would answer, but if he for example, asked me why I use this medication, or I tell him that I don't want to use this medication … I may tell the health educator and she delivers it to the doctor but he doesn't interact with me" (P4).*

These quotations suggest that patient behavior can limit patient involvement in care due to hesitation to ask questions, or patients prefer to interact with the health educator rather than the doctors.

Health provider related barriers

Most participants highlighted that the professional conduct of the healthcare provider was a contributing factor which could obstruct patient involvement in care. One participant commented that the lack of professional ethics and humanity in healthcare when healthcare providers interact with patients acts as a barrier to PCC. He stated that "Dealing with compassion and mercy I see it as non-existent" and "…professional ethics almost do not exist…" (P1). Other participants described the types of healthcare provider behaviors which act as barriers for their involvement in care as: dismissing patient concerns, a lack of eye contact, language barriers, and lack of empathy.

Participants expressed the view that healthcare providers fail to encourage patients to share or ask questions. For example:

> *"I expected him [health provider] to ask me … I had so many questions and I felt that he will ask me about them [questions]… he read the test [results] and wrote the treatment and that's it." (P3).*

Another participant believed that while healthcare providers ask questions, they do so to establish the treatment plan rather than making the patient involved in care.:

> *"Sometimes there are questions…but the questions are not for participation … He [healthcare provider] only takes the information to decide" (P1).*

This might indicate that the current practices of communication and patient involvement in care are more physician centered.

One participant provided an example of poor patient engagement, where their healthcare provider seldomly paid attention or looked at him during the consultation because the healthcare provider focused on their computer, stating:

> *"There was no meeting [eye contact] between me and her [health provider] … [discussing] that the tests were good…. her attention was on the computer" (P2).*

Several patients highlighted a lack of empathy by healthcare provider toward the patient as a barrier to patient involvement in care. For example,

> *"The humanitarian and religious side of dealing with compassion and mercy do not exist. These are financial works that they carry out to earn salaries…." (P1).*

Another described their view of empathy in healthcare interactions in the following way:

> *"…I want him [health provider] to know the path of my disease and interact with me as if he is talking to a friend … so that he knows everything about me … to let me talk." (P2).*

This shows that health providers' lack of empathy would negatively influence patient involvement in care as they dismiss patients' need to interact and share their concerns.

Another factor contributing to the extent of patient involvement in healthcare is a lack of up-to-date knowledge by the provider, with one participant reporting:

> *"Sometimes the patient's information, not medical information, but information about the disease that is equal to the doctor, they [health providers] don't accept it, even in research we [patients] have knowledge about … some doctors don't keep themselves up to date, so they are outdated" (P1).*

Here the patient's differing perspectives on current knowledge with respect to diabetes was not valued and discussed, which undermines the relationship. The same participant believed that he was treated by the healthcare provider in a way where patients were not viewed as individuals but rather as part of a job to gain financial benefits (P1). Another participant commented:

> *"There are doctors, I mean, … his attitude, [is] that I am [the healthcare provider] here to do a job to do what I [healthcare provider] have to do and that's it." (P7).*

These experiences show that behaviors by healthcare providers impact patient involvement in care and that healthcare providers have the opportunity to improve patient involvement by having empathy towards patients and actively encouraging them to share their concerns. Additionally, based on the participants' perspectives, most of the barriers reported were associated with the health provider interpersonal skills, which might affect patient perceptions of their involvement in care.

Environment related barriers

Participants commented on a lack of continuity of care and other elements of healthcare operations that impacted on patient-centered care. For example, seeing different healthcare providers at every appointment or high clinician workloads that limited the time available to them to interact with the healthcare provider. For example, participants stated:

> *"If they [healthcare providers] were not busy, they would sit with you [patient] … and start questioning you and see what you are missing and what you need. If they [healthcare providers] were busy [they say] 'we will communicate with you through WhatsApp' … and they will not respond to you…" (P3).*

> *"…every appointment is with a doctor or [a female] doctor. I feel that you [patient] want to get it over with. You do not have a meeting with someone who knows you and is close to you…. the communication process, it is quite difficult" (P2).*

Many participants also reported long wait times for appointments where it would take four to six months to make an appointment with the healthcare provider.

> *"[the healthcare provider said] that your next appointment will be after six months. This was the first time I took an appointment after six months I felt it is a little faraway and I said, 'that it is fine." (P3).*

During long periods of waiting for appointments one participant expressed the challenge they had in getting in contact with the healthcare provider to have their needs addressed:

> *"You [patient] cannot communicate with him [healthcare provider] with anything no matter what happens to you [outside of their scheduled appointment] … I mean, there is no means of communication at all. They used to have a groups chat, but it was cancelled." (P5).*

This indicates that other barriers might be embedded within the Saudi healthcare system that contributes to the long waiting time and hence work as barriers to patient involvement in care.

Empathy

Despite their individual complaints, the majority of participants spoke about having empathy towards their healthcare providers. They displayed an understanding of how busy the work environment was and therefore the heavy pressure faced by their health providers. One participant stated:

> *"[healthcare providers are] bearing the pressure that occurs throughout the day, so when I come, I do not want to say that he [healthcare provider] does not treat me well. Even if, for example, he [healthcare provider] scolded me or ignored me at the same time for me, its fine … he is a person who is experiencing stress and going through a stage that he has many patients… I would understand that they [healthcare providers] have many patients, and I am not the only patient." (P4).*

Another participant stated that there is a:

> *"…lot of pressure on them [healthcare provider]. He [healthcare provider] cannot give you [patient] enough time in order to understand you and listen to what you have because I mean I feel for them that he [healthcare provider] is stressed and that he has so many patients" (P5).*

Effective communication

Effective communication is viewed as an integral component of patient provider interactions. Participants stated that healthcare providers asked them about their conditions and encouraged them to express their concerns. Participants spoke about experiences of good practitioner communication. For example:

> *"…. I used to meet doctors, frankly. I mean, I can't praise them enough. There was an eye contact. They asked me about my condition" (P3).*

> *"She [healthcare provider] asked about me, 'what do you [patient] have? what are the things that you complain about?'… I told her I have the heart condition …. and she helped me to get comfort and treatment and she connected me …. she connected me to another doctor in another clinic" (P5).*

Another participant stated that good communication skills were essential to encouraging and motivating patients to share their concerns during a consultation:

> *"He really left room for me to speak, I mean, I think on the last visit, I could have talked for about half an hour" (P7).*

One participant commented that having a "friendship" with the healthcare provider would simplify the communication process. She stated:

> *"If [the relationship] is not formal then everything is fine…. he [healthcare provider] has no problems to hear from you [patient] all the time and gives solutions. If it was a formal relationship you [patient] will not be able to discuss with him [healthcare provider] because he doesn't like to talk so much and doesn't want problems so you will remain silent but if it was almost as we said that it is a friendship or something like that, this for me is more important than the quality itself." (P7).*

Patients' descriptions of positive healthcare provider characteristics during interactions were focused on actively listening to patients, positivity, patience, and the ability of providers to put themselves in the place of the patient. The following quotations provide an account of the ideal practitioner from the participant's perspective:

> *"First, to be smiling, cheerful … to accept the patient as he is, to listen to him … to be familiar with the aspects of the disease that he treats, and to be aware of the capabilities and tools he possesses …in the health facility in which he works, so that he is deal-*

ing with reality.... to be realistic with the patient ... earns his [patient's] affection and their interactions would be based on honesty" (P6).

"To put himself in the place of the patient I mean, ... To feel the patient's feelings and make him feel .... That when [the patient] is talking, he is not wasting time..." (P5).

Participants variously emphasized that healthcare providers should have "patience", "endurance", "understanding", should "support patients", "put themselves in [the] patient's place", "ask more questions", "encourage patients to talk", and use "motivational phrases" which would influence the patient to actively participate in their care.

Culture

Several participants expressed factors related to Saudi Arabian culture related to gender and cultural that influenced their interactions with their healthcare providers.

Gender role

The role of gender in impacting patient provider interactions differed among the participants. A few participants commented on their preference to receive care from a healthcare provider of the same gender. This view could reflect cultural practices. One male respondent expressed the need to interact with a male healthcare provider when he wanted to discuss relationship issues:

"There is a big difference..... The culture of society affects. Yes, I cannot say some things, for example, except when I am with a [male] doctor ... I mean, it is possible in matters related to my relationship with the other party [wife]" (P2).

Another female participant stated that in general she was more comfortable to have a female healthcare provider under the assumption that she can bond with her better due to their shared gender. She commented:

"Yes, it makes a difference when the healthcare provider is a female, I can interact with her and deal with her that she is the same gender. She can understand me more when I explain, I will be comfortable that I explain and talk to her .... While a man, I will not be able to interact with him" (P4).

However, this view was not shared by all respondents as one female participant commented:

"For me, I do not feel any difference, in the end, they [healthcare providers] are all performing the same mission and message" (P3).

A similar view was expressed by another male participant who indicated that the gender of the healthcare provider is not important as long as the healthcare provider actively involves patients in a conversation. Another also commented that what matters is the healthcare provider's attitude, which affects patient provider communication. He stated:

"I do not [see] any difference. The same ethics, the same method, and the same treatment, ... I mean ... they teach each other a way of interacting [it is] the same thing, whether the healthcare provider is male or female." (P1).

For these participants the gender of the healthcare provider was not a significant factor, with provider behavior instead the most significant factor in facilitating patient involvement.

Cultural norms

In Saudi culture, which is strongly influenced by Islam, the young are strongly expected to respect their elders [46, 47]. This is reflected in the views of one female participant, who commented:

"... I always respect that he [healthcare provider] is older than me and is talking to my mother. I mean, I just listen to their interaction ..." (P4).

Saudi Arabia culture is also collectivist rather than individualist, however, only one participant reported a form of family involvement in care. For this participant her needs were dismissed by her healthcare providers who instead involved her family in decision making about her care. She stated,

"They [healthcare providers] did not give me the freedom to speak... the whole questions weren't directed at me ... the questions were directed to my mother and father and not me. I tried to explain to them that I understand the diabetes and I have been living with diabetes for 19 years therefore I understand my condition, but they prefer to listen to my mother instead of me" (P4).

This suggests that the Saudi Arabian culture have a significant influence on patient-provider interaction and hence patient involvement in decision making.

Discussion

As far as we are aware this is the first paper to explore patient perceptions of their involvement in healthcare in Saudi Arabia. The main themes emerging from this exploratory study reveal important insights about the

nature of patient involvement in Saudi Arabia by providing qualitative data from in-depth interviews with patients.

Mis-conceptualization of patient involvement and patient role

Our study showed that most participants had minimal knowledge of patient involvement in care. This was consistent with previous studies in other contexts that have investigated patient perceptions of involvement in decision making in cancer [48] and diabetes [49]. Those studies found that patients had limited knowledge of concepts of shared decision making and that their preferences were more focused on sharing information rather than sharing decision making [48, 49]. There are several factors that contribute to patients' minimal knowledge of their role in care. First, PCC is considered new in some healthcare organizations in Saudi Arabia [27], with patients lacking understanding of their rights to be involved in care [29]. It may also be due to the nature of power dynamics between patients and healthcare providers in Saudi Arabia where patients perceive healthcare providers as authoritative figures whose words should be trusted in an unquestioning way [50].

In our study patient willingness to participate in healthcare decision making was affected by their type of involvement, however in general participants were found to take a minor role in decision making and rely on health providers' expertise. This finding reflects patient involvement norms beyond the Middle East and North Africa (MENA) region. For example, a national survey of 2765 people in the United States of America aiming to evaluate preferences for participating in decision-making found that 96% preferred to have a choice and to be asked for their opinion [51]. However, participants' responses varied in the degree to which they would rely on the healthcare provider's medical knowledge. About 44% of participants preferred to depend on the healthcare providers' medical knowledge rather than exploring information themselves, and 52% preferred to leave final decision-making to their health provider [51]. In our study we found that participants preferred to have an active role in behavioural decisions such as adopting a healthy lifestyle (e.g., decisions about diet and exercise). These results are in line with the study by Mansell, et al. [52], which investigated whether the type of illness and the nature of decision making predicts patient preferences to be involved in decision making. The study found that patients preferred to be actively involved in major decisions such as surgery and in behavioural change a decisions such as diet and exercise while they preferred to be less involved in minor decisions such as ordering blood tests.

Previous literature has emphasized the importance of having mutual interactions between patients and healthcare providers where information is shared between them as this gives patients the opportunity to feel in control and responsible for their care, and therefore involved in their care [53–56]. There is an inherent power imbalance to the relationship between healthcare providers and patients which derives from the vulnerability of patients who come seeking help, in relation to the healthcare provider's expert knowledge [57]. There is also a contributing role for culture, where patient involvement may be further limited by the privileged role health practitioners hold in some societies in the MENA region, such as Pakistan, Jordan, and Saudi Arabia [50, 58–60]. In the current study participants showed support for the concept of patient involvement but described their role as predominantly involving information provision to healthcare providers and compliance with healthcare provider instructions. This misunderstanding of the full dimensions of patient participation, as described by the models outlined earlier, points to the importance of increasing awareness of what and how patients in Saudi Arabia can be active participants in care. Increasing knowledge of patient participation and the benefits associated with it, which include improving the level of self-care behaviors, adherence to medications, and overcoming illness related stress and anxiety [5, 61], could in turn positively influence expectations and preferences to be involved [62, 63]. In addition, health organizations in Saudi Arabia need to enable this within a supportive environment in which health providers have a positive attitude and encourage patients to take an active role in care which would, in turn, increase patient involvement in care [48].

Barriers to patient involvement

Our findings show that healthcare provider communication style can be an important enabler or barrier to person centred care. Effective communication has been clearly established as an essential element that health providers need to practise in order to provide high-quality person-centred care [64, 65]. Examples of effective communication skills are asking open ended questions, active listening, attentiveness to patients' needs and giving patients time to respond [64, 66, 67]. Participants in this study felt that healthcare providers needed to ask questions and motivate patients to express their needs and concerns. However, according to our participants, health providers often failed to practise these features of effective communication. This finding is supported by research from the MENA region and elsewhere which has shown that most of the reported barriers to patient centred care are focused on healthcare provider behaviour [68–70]. Problematic behaviours identified in other

literature includes limited eye contact and dismissing patient concerns [68–70].

Our study found that participants preferred a healthcare provider who shows empathy towards them and listens to their needs. This is consistent with previous studies which have reported that patients prefer healthcare providers who have a positive attitude expressed through actions such as smiling and expressing humour during interactions [71]. However, participants in our study felt that there was a lack of empathy towards them by healthcare providers, including healthcare providers viewing them as just a part of their work rather than as a human being. To address this providing medical students and healthcare providers with empathetic communication skills has been identified as important for positive patient outcomes [72–74]. Our findings suggest that more emphasis should be placed on the development of supportive and therapeutic relationships between patients and healthcare providers in Saudi Arabia in order to establish a role for patients in their own healthcare. Moudatsou et al. [75] reported that healthcare providers find it challenging to be empathetic due to factors which include high patient load and lack of time provided to spend with the patient. Our results reveal that patients have empathy towards their healthcare providers, showing that patients understand the work burden associated with healthcare work environments. This may be as a result of cultural perceptions of healthcare providers in the Saudi community where healthcare providers hold an authoritative position and should be respected and trusted [50].

In Saudi Arabia, culture is strongly influenced by Islam as the Islamic religion dictates the way of life [47]. Gender is culturally constructed in this context and therefore some participants in this study preferred healthcare providers of the same gender in order to receive healthcare that was centred on their needs. This reflects findings of previous research that highlights the significance of providing services in accordance with gender-based norms in relation to patient-provider relationships [76, 77]. In this study one participant also spoke about healthcare providers preferring to involve their family in decision making rather than involving the patient themself. This attitude might be as a result of healthcare provider belief that families have a full knowledge of patient health status [78, 79]. This finding supports previous research which has reflected on the role of family in patient care in the MENA region [58, 60, 70]. According to Hofstede, et al. [80], the nature of culture and power distribution in a society influences the practice of PCC. Hence, it appears that the practice of PCC in Saudi Arabia is influenced by an unequal distribution of power and dependent collectivism. Consequently, there is a need to understand and build PCC culture in Saudi Arabia through establishing frameworks with a central focus on culture [81] .

The findings of this study show that there is still much to do to educate patients about their involvement in care in Saudi Arabia. Consequently, health organizations in Saudi Arabia need to work more to educate both patients and healthcare providers in order to achieve optimal PCC. The Ministry of Health should explore the development of a culturally sensitive patient-centred care model that aligns with the values and norms of Saudi Arabian culture. This research underscores the importance of enhancing patient education regarding their active role in their own care, while also emphasizing the significance of equipping healthcare providers with proficient interpersonal skills to ensure effective implementation. This approach could significantly contribute to the enhancement of healthcare quality within the country. Further research building on this exploratory research is needed to determine how patients view their role and their involvement in care, to examine what factors influence their involvement in Saudi Arabia and to develop relevant models based on this, which can then be put into practice in improving the practice of PCC in Saudi Arabia.

Study limitations

Our data is an exploratory study which has provided deep understanding of patient perspectives on patient involvement in healthcare in Saudi Arabia. In doing so it provides deep and personal reflections but is limited by only representing the views of diabetic patients who received care in the diabatic centre at King Abdul Aziz Specialist Hospital. Given this limitation we recommend a national investigation regarding public awareness of the role of patients in care in Saudi Arabia. As qualitative research is focused on opinions and judgments based on personal experiences rather than categorical results, future work should expand on this exploratory study by bringing in a larger number of participants from different disease groups, and their carers, and contrasting patient perspectives with those of their healthcare providers regarding the challenges of practising patient centred care.

Conclusion

This study explored current practices of patient involvement in healthcare from the perspective of diabetes patients in Saudi Arabia. Based on the results reported, there is a clear need to increase both patient and healthcare provider education and awareness of patient involvement in Saudi Arabia. By educating patients about the possibilities of patient involvement and explaining their role it will make it easier for patients to understand appropriate levels of involvement. On the other hand, there is a need to provide healthcare providers with explicit training on PCC and interpersonal skills to

facilitate patient involvement in care. The findings of the current study have potential implications for improving the quality of care in Saudi Arabia through shaping education and training for both patients and healthcare providers regarding patient involvement and interpersonal skills.

Abbreviations

PCC Patient centered care
IOM Institute of Medicine
MENA Middle East and North Africa

Acknowledgements
We acknowledge King Abdulaziz specialist hospital for their cooperation. We extend our gratitude to research participants who graciously devoted their time to participate in the interviews. A special thanks go to Abdulellah Al Thobaity, Amal Alsofiani and Mona Alqurashi for their valuable role in in the recruitment phase of this paper.

Author contributions
RAA, JSM and RF were responsible for the study design and data analysis. RAA, JSM and RF contributed to the drafting of the article and the final approval of the article.

Funding
The lead author is supported by a PhD scholarship from Taif university.

Data Availability
Due to the ethical requirements of the study and the need to maintain confidentiality for the participants, the full transcripts which constitute this research data are not available for sharing.

Declarations

Ethics approval and consent to participate
Ethical approval was obtained from the University of Sydney and from the Saudi Arabia Directorate of Health Affairs Taif Institutional Review Board. Informed consent was obtained from participants and all participants were informed that their participation was voluntary. All methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

Received: 9 December 2022 / Accepted: 28 November 2023
Published online: 14 December 2023

References

1. Alhaqwi A, Aldrees T, Alrumayyan A, Alfarhan A, Badri M. Patient's desire and preference for provision of information toward greater involvement in shared care. Saudi J Med Med Sci. 2016;4(3):172–7.
2. Richardson WC, Berwick DM, Bisgard J, Bristow L, Buck C, Cassel C. Crossing the quality chasm: a new health system for the 21st century. In.: Washington, DC: National Academy Press; 2001.
3. Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. J Gen Intern Medicine: JGIM. 2012;27(5):520–6.
4. Griffin SJ, Kinmonth A-L, Veltman MWM, Gillard S, Grant J, Stewart M. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. Ann Fam Med. 2004;2(6):595–608.
5. Peimani M, Nasli-Esfahani E, Sadeghi R. Patients' perceptions of patient–provider communication and Diabetes care: a systematic review of quantitative and qualitative studies. Chronic Illn. 2020;16(1):3–22.
6. Rao JK, Anderson LA, Inui TS, Frankel RM. Communication interventions make a difference in conversations between Physicians and patients: a systematic review of the evidence. Med Care. 2007;45(4):340–9.
7. Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, Jordan J. The impact of patient-centered care on outcomes. J Fam Pract. 2000;49(9):796–804.
8. Ulin K, Malm D, Nygårdh A. What is known about the benefits of patient-centered care in patients with Heart Failure. Curr Heart Fail Rep. 2015;12(6):350–9.
9. Corbett LQ, Ennis WJ. What do patients want? Patient preference in wound care. Mary Ann Liebert, Inc. 140 Huguenot Street, 3rd Floor New Rochelle. NY 10801 USA; 2014.
10. Sandman L, Munthe C. Shared decision making, Paternalism and Patient Choice. Health Care Anal. 2010;18(1):60–84.
11. Couët N, Desroches S, Robitaille H, Vaillancourt H, Leblanc A, Turcotte S, Elwyn G, Légaré F. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. Health Expect. 2015;18(4):542–61.
12. Greenfield S, Kaplan S, Ware JE Jr. Expanding patient involvement in care: effects on patient outcomes. Ann Intern Med. 1985;102(4):520–8.
13. Principles of Person Centred Care. [https://www.picker.org/about-us/picker-principles-of-person-centred-care/].
14. Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: a systematic review of the literature. Med care Res Rev. 2013;70(4):351–79.
15. Frampton S, Guastello S, Brady C, Hale M, Horowitz SM, Smith SB, Stone S. Patient-centered care: improvement guide. 2008.
16. Frampton SB. Planetree patient-centered care and the Healing arts. Complement Health Pract Rev. 2001;7(1):17–9.
17. Frampton SB, Gilpin L, Charmel PA. Putting patients first: Designing and practicing patient-centered care. 2003.
18. Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G. Patient preferences for shared decisions: a systematic review. Patient Educ Couns. 2012;86(1):9–18.
19. Arora NK, McHorney CA. Patient preferences for medical decision making: who really wants to participate? Medical care 2000:335–341.
20. Flynn KE, Smith MA, Vanness D. A typology of preferences for participation in healthcare decision making. Soc Sci Med. 2006;63(5):1158–69.
21. Ryan J, Sysko J. The contingency of patient preferences for involvement in health decision making. Health Care Manage Rev. 2007;32(1):30–6.
22. Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical decision making: a review of published surveys. Behav Med. 1998;24(2):81–8.
23. Murray E, Pollack L, White M, Lo B. Clinical decision-making: patients' preferences and experiences. Patient Educ Couns. 2007;65(2):189–96.
24. Alsulamy N, Lee A, Thokala P, Alessa T. Views of stakeholders on factors influencing shared decision-making in the Eastern Mediterranean Region: a systematic review. East Mediterr Health J. 2021;27(3):300–11.
25. Akkafi M, Sajadi HS, Sajadi ZS, Krupat E. Attitudes toward patient-centered care in the Mental Care Services in Isfahan, Iran. Commun Ment Health J. 2019;55(3):548–52.
26. Schattner A, Bronstein A, Jellin N. Information and shared decision-making are top patients' priorities. BMC Health Serv Res. 2006;6(1):21–1.
27. Al-Sahli B, Eldali A, Aljuaid M, Al-Surimi K. Person-centered care in a Tertiary Hospital through Patient's eyes: a cross-sectional study. Patient Prefer Adherence. 2021;15:761.
28. Ahmad S, Singh J, Kamal MA, Shaikh ZM. Person-centered care design with reference to healthcare outcomes in Saudi Arabia: an overview. Am J Civ Eng Archit. 2020;8(3):91–6.
29. Almoajel AM. Hospitalized patients' awareness of their rights in Saudi governmental hospital. Middle-East J Sci Res. 2012;11(3):329–35.
30. AlHaqwi AI, AlDrees TM, AlRumayyan A, AlFarhan AI, Alotaibi SS, AlKhashan HI, Badri M. Shared clinical decision making: a Saudi Arabian perspective. Saudi Med J. 2015;36(12):1472.
31. Aljaffary A, Alhuseini M, Rayes SA, Alrawiai S, Hariri B, Alumran A. The OPTION scale: measuring patients' perceptions of Shared decision-making in the Kingdom of Saudi Arabia.(ORIGINAL RESEARCH). J Multidisciplinary Healthc. 2020;13:1337–46.
32. Nam S, Chesla C, Stotts NA, Kroon L, Janson SL. Barriers to Diabetes management: patient and provider factors. Diabetes Res Clin Pract. 2011;93(1):1–9.
33. Almutairi KM. Quality of Diabetes management in Saudi Arabia: a review of existing barriers. Arch Iran Med. 2015;18(12):816–21.
34. World Health Organization. Definition, diagnosis and classification of Diabetes Mellitus and its Complications: report of a WHO consultation. Part 1,

diagnosis and classification of Diabetes Mellitus. In.: World health organization; 1999.
35. McBride E, Hacking B, O'Carroll R, Young M, Jahr J, Borthwick C, Callander A, Berrada Z. Increasing patient involvement in the diabetic foot pathway: a pilot randomized controlled trial. Diabet Med. 2016;33(11):1483–92.
36. Entwistle V, Prior M, Skea ZC, Francis JJ. Involvement in treatment decision-making: its meaning to people with Diabetes and implications for conceptualisation. Soc Sci Med. 2008;66(2):362–75.
37. Funnell MM. Patient empowerment. Crit Care Nurs Q. 2004;27(2):201–4.
38. Ritchie J, Lewis J, Nicholls CM, Ormston R. Qualitative research practice: a guide for social science students. and researchers: sage; 2013.
39. Maxwell JA. Qualitative research design: an interactive approach. Sage publications; 2012.
40. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.
41. Abdelhafeez S, Al-Swat H, Babiker S, Nasir O, Eisa B. The prevalence of Diabetes Mellitus in Taif Region, Saudi Arabia during 2013–2014. International Journal of Science and Research (IJSR); 2018.
42. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res. 2016;26(13):1753–60.
43. Lincoln YS, Guba EG. Naturalistic inquiryBeverly Hills. Calif: Sage Publications; 1985.
44. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Res Psychol. 2006;3(2):77–101.
45. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. Qualitative Res Sport Exerc Health. 2021;13(2):201–16.
46. Ahmed AS. Discovering Islam: making sense of Muslim History and Society. Routledge; 1988.
47. Saleh Al Mutair A, Plummer V, Paul O'Brien A, Clerehan R. Providing culturally congruent care for Saudi patients and their families. Contemp Nurse. 2014;46(2):254–8.
48. Sainio C, Eriksson E, Lauri S. Patient participation in decision making about care: the cancer patient's point of view. Cancer Nurs. 2001;24(3):172–9.
49. Peek ME, Quinn MT, Gorawara-Bhat R, Odoms-Young A, Wilson SC, Chin MH. How is shared decision-making defined among african-americans with Diabetes? Patient education and counseling 2008, 72(3):450–8.
50. Banaser M, Stoddart K, Cunningham N. A qualitative study of patient satisfaction in oncology wards setting in Saudi Arabia. Research and Reviews: Journal of Nursing and Health Sciences 2017, 3(3):85–97.
51. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making: a national study of public preferences. J Gen Intern Medicine: JGIM. 2005;20(6):531–5.
52. Mansell D, Poses RM, Kazis L, Duefield CA. Clinical Factors That Influence Patients' Desire for Participation in Decisions About Illness. Archives of internal medicine (1960) 2000, 160(19):2991–2996.
53. Eldh AC, Ehnfors M, Ekman I. The Phenomena of participation and non-participation in Health Care-experiences of patients attending a nurse-led clinic for Chronic Heart Failure. Eur J Cardiovasc Nursing: J Working Group Cardiovasc Nurs Eur Soc Cardiol. 2004;3(3):239–46.
54. Eldh AC, Ekman I, Ehnfors M. Conditions for patient participation and non-participation in Health Care. Nurs Ethics. 2006;13(5):503–14.
55. Tutton EMM. Patient participation on a ward for frail older people. J Adv Nurs. 2005;50(2):143–52.
56. Vahdat S, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. Patient involvement in Health Care decision making: a review. Iran Red Crescent Med J 2014, 16(1).
57. Koeck C. Imbalance of power between patients and doctors. Volume 349. British Medical Journal Publishing Group; 2014.
58. Baig AM, Humayaun A, Mehmood S, Akram MW, Raza SA, Shakoori T. Qualitative exploration of factors associated with shared decision-making in Diabetes management: a healthcare provider's perspective. Int J Qual Health Care. 2020;32(7):464–9.
59. Matusitz J, Spear J. Doctor-Patient Communication styles: a comparison between the United States and three Asian countries. J Hum Behav Social Environ. 2015;25(8):871–84.
60. Obeidat R, Lally R. Jordanian physicians' perceived barriers and facilitators to patient participation in treatment decision-making: an exploratory study. Indian J Cancer. 2018;55(4):377–81.
61. Mead EL, Doorenbos AZ, Javid SH, Haozous EA, Arviso Alvord L, Flum DR, Morris AM. Shared decision-making for Cancer Care among racial and ethnic minorities: a systematic review. Am J Public Health. 2013;103(12):e15–e29.
62. Bastiaens H, Van Royen P, Pavlic DR, Raposo V, Baker R. Older people's preferences for involvement in their own care: a qualitative study in primary healthcare in 11 European countries. Patient Educ Couns. 2007;68(1):33–42.
63. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: a narrative review. Patient Educ Couns. 2006;60(2):102–14.
64. Robinson JH, Callister LC, Berry JA, Dearing KA. Patient-centered care and adherence: definitions and applications to improve outcomes. J Am Acad Nurse Pract. 2008;20(12):600–7.
65. National Center for Health S. : Healthy People 2010 Final Review. In.; 2012.
66. Howie JGR, Heaney D, Maxwell M. Quality, core values and the general practice consultation: issues of definition, measurement and delivery. Fam Pract. 2004;21(4):458–68.
67. Amin N, Cunningham SJ, Jones EM, Ryan FS. Investigating perceptions of patient-centred care in orthodontics. J Orthodont. 2020;47(4):320–9.
68. Peek ME, Wilson SC, Gorawara-Bhat R, Odoms-Young A, Quinn MT, Chin MH. Barriers and facilitators to Shared decision-making among African-americans with Diabetes. J Gen Intern Medicine: JGIM. 2009;24(10):1135–9.
69. Aminaie N, Mirlashari J, Lehto R, Lashkari M, Negarandeh R. Iranian Cancer patients perceptions of barriers to participation in Decision-Making: potential impact on patient-centered care. Asia-Pacific J Oncol Nurs. 2019;6(4):372–80.
70. Abdulhadi N, Al Shafaee M, Freudenthal S, Ostenson C-G, Wahlström R. Patient-provider interaction from the perspectives of type 2 Diabetes patients in Muscat, Oman: a qualitative study. BMC Health Serv Res. 2007;7(1):162–2.
71. Brown RF, Butow PN, Henman M, Dunn SM, Boyle F, Tattersall MH. Responding to the active and passive patient: flexibility is the key. Health Expect. 2002;5(3):236–45.
72. Ward J, Cody J, Schaal M, Hojat M. The empathy enigma: an empirical study of decline in empathy among undergraduate nursing students. J Prof Nurs. 2012;28(1):34–40.
73. Pereira L, Figueiredo-Braga M, Carvalho IP. Preoperative anxiety in ambulatory Surgery: the impact of an empathic patient-centered approach on psychological and clinical outcomes. Patient Educ Couns. 2016;99(5):733–8.
74. Ghiyasvandian S, Abdolrahimi M, Zakerimoghadam M, Ebadi A. Therapeutic communication of Iranian nursing students: a qualitative study. Pertanika J Social Sci Humanit. 2018;26(3):1757–74.
75. Moudatsou M, Stavropoulou A, Philalithis A, Koukouli S. The role of Empathy in Health and Social Care professionals. Healthcare. 2020;8(1):26.
76. Hasnain M, Connell KJ, Menon U, Tranmer PA. Patient-centered care for Muslim women: Provider and patient perspectives. J Women's Health. 2011;20(1):73–83.
77. Tsianakas V, Liamputtong P. What women from an Islamic background in Australia say about care in pregnancy and prenatal testing. Midwifery. 2002;18(1):25–34.
78. Shibily FM, Aljohani NS, Aljefri YM, Almutairi AS, Almutairi WZ, Alhallafi MA, Alsharif F, Almutairi W, Badr H. The perceptions of nurses and nursing students regarding family involvement in the care of hospitalized adult patients. Nursing reports. (Pavia Italy). 2021;11(1):133–42.
79. Fernandes C, Gomes J, Martins MM, Gomes B, Gonçalves L. The importance of families in nursing care: nurses' attitudes in the hospital environment. Revista De Enfermagem referência. 2015;4(7):21–30.
80. Hofstede G, Hofstede GJ, Minkov M. Cultures and organizations : software of the mind : intercultural cooperation and its importance for survival, Revised and expanded 3rd edition. New York: McGraw-Hill; 2010.
81. Abouqal R, Phua J, Arabi YM. Patient-physician relationship in specific cultural settings. Intensive Care Med. 2018;44(5):646–8.

Publisher's Note

CHAPTER 6

MEASURING DIABETIC PATIENTS' PERCEPTIONS OF PATIENT-CENTRED CARE IN SAUDI ARABIA

Abstract

Introduction: Although patient-centred care (PCC) is recognised as a crucial approach for improving patient health outcomes, studies exploring the implementation of PCC are lacking in Saudi Arabia. We addressed this gap by exploring the perceptions of people living with diabetes in Saudi Arabia with regard to their interactions with their healthcare providers.

Methods: Participants completed the Patient-Provider Interaction Questionnaire (PPIQ), which measures perceptions of patient-centred interactions. An open-ended question asked patients about their ideal role in healthcare. The questionnaires were distributed using the WhatsApp application between January and June 2022 to diabetic patients in Saudi Arabia.

Results: A total of 116 respondents completed the questionnaire. Of these, 52% were male and 39% were aged 18-39. The overall mean PCC score was 63/80, indicating that patients experienced PCC in their interactions with healthcare providers. No significant associations were found between patient characteristics and their perception of PCC, apart from treatment region. Patients treated in the Western region had significantly higher overall PCC score and scores for all PCC subscales - *effective communication* (P <.001), *interest in patients agenda* (P= .005), *empathy* (P <.001) and *patient involvement in care* (P= .03) - compared with patients treated in other regions on Student two-sample t tests. The responses to the open-ended question identified two major themes 1) the patient's role as a passive recipient in care,

and 2) an authoritative role of the healthcare provider in provision of care. Responses indicated a lack of patient awareness of the potential for a greater extent of their role in care.

Conclusion: Patients believed that they experienced PCC in their interactions with healthcare providers and were unaware that they could have a more involved role. There is a need for PCC to be fostered further in healthcare in Saudi Arabia through patient education about their role in care, and healthcare practices to facilitate patients' awareness of their involvement in care.

Keywords: patient-centred care, patient involvement, diabetic patients, Saudi Arabia

Background

Diabetes Mellitus (DM) is a public health concern worldwide due to its potential severe impacts on patient health, including loss of vision, renal failure, cardiovascular disease, peripheral vascular disease and cerebrovascular diseases, sexual dysfunction and neuropathy (World Health Organization, 1999, 2016). These sequelae result in serious financial costs to healthcare systems. The global expenditure due to diabetes was US$966 billion in 2021and it is expected to increase to over US$1.054 billion by 2045 (International Diabetes Federation, 2021). According to the International Diabetes Federation, in 2021, diabetes affected approximately 536.6 million people worldwide, with numbers expected to increase to over 783.2 million by 2045. Saudi Arabia has one of the highest diabetic prevalence rates within the Middle Eastern and North African region with prevalence increasing from 2.8 million people in 2011 to 4.3 million in 2021 (International Diabetes Federation, 2021). The increased prevalence of diabetes in the Kingdom of Saudi Arabia is associated with economic growth which has led to lifestyle changes such as increasing lack of exercise and unhealthy diet, and increased prevalence of obesity and overweight status (Naeem, 2015).

Diabetic patients' self-care management practices are considered crucial to maintaining diabetic control and reducing risk of diabetic complications (Saad et al., 2018). However, many studies in Saudi Arabia have reported patients' poor performance in self-care activities, including glucose monitoring, foot care, and adherence to diet and exercise recommendations, although medication adherence was relatively high (Alhaiti et al., 2020; Alotaibi, 2020). Adopting a patient-centred approach as the preferred model of care is critical for patients with chronic illnesses such as diabetes who need support for self-management of disease. This is because the patient-centred care (PCC) model views patients and their family members as individuals, recognising their needs and involving them in care-related decisions

(Mead & Bower, 2000), thus improving their engagement and motivation for self-care (Akturan et al., 2016; Mohamed et al., 2013). A growing body of literature shows that practicing PCC leads to better patient outcomes (Rathert et al., 2013), including improved patient health status and reduced need for tests and referrals (Stewart et al., 2000). Evidence show that patient involvement in care is associated with improved adoption of healthy behaviours, such as improved adherence to diet and exercise regimes (Miller, 2016). The 2012 position statement released by the American Diabetes Association and the European Association for the Study of Diabetes emphasised the importance of adopting a PCC approach (Inzucchi et al., 2012).

To develop and implement person-centred care (PCC) in health service delivery, it is crucial to comprehend patients' perceptions of their involvement in care, including the extent to which healthcare providers incorporate PCC in health encounters (Al-Tannir et al., 2017). Furthermore, a deep understanding of the patient perspective is vital for successfully implementing and evaluating PCC (Rawaf et al., 2011). However, developing and implementing practices that encourage patient involvement are often seen as a challenge (Al-Tannir et al., 2017; Kovacs Burns et al., 2014). While patient involvement models have been successfully implemented in many Western countries (Al-Tannir et al., 2017), the Ministry of Health in Saudi Arabia has identified patient involvement as a future strategy rather than as an immediate priority (Al-Sahli et al., 2021; Ministry of Health's Vision Realization Office, 2019). It is important that healthcare providers and policymakers in Saudi Arabia work together to develop a healthcare system that is more patient-centred (Al-Sahli et al., 2021) and that this work is underpinned by findings from research.

Although the PCC model states that patients' needs and satisfaction must be prioritised in healthcare, in practice the model mainly relies on healthcare providers to develop and

practice good interpersonal communication skills during consultations to achieve this (Reynolds, 2009). Evidence shows that several barriers exist to impact the process of patient-provider communication. For example, a recent review of patient-provider communication in Saudi Arabia highlighted barriers to patient-provider interaction relating to language, culture, the religious knowledge of health providers and limited interactions between patients and non-Arabic-speaking healthcare providers (Alshammari et al., 2019).

Few studies in Saudi Arabia have focused on patient perspectives of PCC. Two existing studies have focused on patient perception of their involvement in care (Aljaffary et al., 2020; Aljaffary et al., 2022) and one study has focused on patients perceptions of the healthcare environment in relation to PCC (Al-Sahli et al., 2021). For example, a study conducted in Saudi Arabia to assess patient perceptions of involvement in care during clinical encounters found that patients have a positive attitude towards patient involvement practices (Aljaffary et al., 2020). A cross-sectional study assessed patient experiences of their involvement in care within a tertiary hospital in central Riyadh, Saudi Arabia. In this study, 73% of patients felt they were involved in care (Al-Tannir et al., 2017). Another study conducted in Saudi Arabia found a positive association between patient *awareness* of shared decision making and their *preference* for shared decision-making (Aljaffary et al., 2022). This suggests that the more patients are aware of shared decision-making, the more they prefer to be involved in care. Furthermore, a relatively large study (N=300) examining patient perceptions toward the climate of PCC and associated factors in a tertiary hospital in Saudi Arabia found that patient perceptions towards PCC were positive, and that patient and hospital characteristics played an essential role in shaping patient perceptions toward PCC. For example, male patients were found to prefer to participate in care more than female participants (Al-Sahli et al., 2021).

Despite the growing interest in Saudi Arabia in the implementation of PCC, there is a limited body of research addressing patient perspectives of patient-centred care (PCC), and the existing studies in this area have certain limitations. Specifically, some studies have failed to examine the dynamics of patient-provider interaction (Al-Sahli et al., 2021). Another limitation is a primary focus on exploring patient preferences regarding involvement in care, rather than capturing their actual experiences of being involved in care (Aljaffary et al., 2022). Furthermore, certain investigations have been constrained to specific healthcare settings and population subsets, restricting the generalisability of their findings (Al-Tannir et al., 2017). As a result, there remains a need for further research that encompasses a broader range of patient perspectives and addresses the actual experiences of patient-provider interactions in Saudi Arabia. There have been no studies which have focused on diabetic patient experiences of their interactions with healthcare providers. Diabetic patients are a crucial population that would benefit from wide implementation of PCC in Saudi Arabia given the high prevalence of diabetes (over 4 million people in 2021 (International Diabetes Federation, 2021)) and expected to grow significantly, reaching approximately 7 million people by 2045 (IDF Diabetes Atlas, 2021) and the importance of self-management for improving their health outcomes (Akturan et al., 2016; AlHaqwi et al., 2023; Mohamed et al., 2013). Hence, given the dearth of existing literature in Saudi Arabia reinforcing the need to implement patient-centred approaches in diabetes care, we sought to assess the perceptions of people living with diabetes with regards to their interactions with their healthcare providers.

Methods

This study investigated patient perceptions of their interactions with their healthcare providers in order to understand attitudes towards practising patient-centred care in Saudi Arabia. The results presented in this publication are part of a broader mixed methods study

that compares patient and healthcare providers' attitudes toward PCC in Saudi Arabia. In this publication we present only the data on patient perceptions of PCC.

Participants

Participants in this study were diabetic patients living in Saudi Arabia. We followed purposive sampling and snowballing techniques to identify participants. The questionnaire targeted people who were at least 18 years of age, had been living with type 1 or type 2 diabetes mellitus, were currently receiving care at a diabetic centre in Saudi Arabia and could speak and understand written Arabic or English. The study invitation was sent to diabetic patients by healthcare providers working in the diabetic centre at King Abdul-Aziz Specialist Hospital through a message via the WhatsApp messaging application and participants were asked to refer the study to other patients who met the inclusion criteria. Interested participants accessed the survey via a link in the WhatsApp message that redirected them to the Qualtrics hosted online survey. The data collection was conducted between January to June 2022.

Questionnaire

The survey questionnaire administered to patients within this study comprised three sections. The first section asked about the participant's sociodemographic characteristics. In the second section, we adapted the English version of the validated questionnaire Patient-Provider Interaction Questionnaire (PPIQ) developed by Casu et al. (2019) to assess patients' perceptions of their interactions with healthcare providers from the patient's perspective . The questionnaire comprised 16 items covering four subscales of PCC described as follows:

- **Effective communication** refers to healthcare provider skills in questioning and interacting with patients.

- **Interest in patient agenda** refers to health providers' interest in what the patient needs and expects from care.
- **Empathy** refers to the healthcare providers' ability to understand patient emotion and put themselves in the patient's place.
- **Patient involvement in care** refers to the extent to which the healthcare provider allows patients to talk and make decisions (Casu et al., 2019).

The reliability of the English instrument was assessed using the Cronbach's alpha value. Casu et al. (2019) reported optimal internal consistency, with a reported Cronbach's alpha coefficient of 0.95 for the overall PCC score and values of 0.86, 0.92, 0.76 and 0.85 for the four subscales of *effective communication, interest in patients' agenda, empathy* and *patient involvement in care*, respectively. According to Tavakol and Dennick (Tavakol & Dennick, 2011), values of 0.7 and above for Cronbach's alpha coefficient are acceptable. The English version of the questionnaire was adapted and translated from English to Arabic by independent professional translators using a forward-backward method and modified following recommendations provided by experts who are specialised in Arabic literature and applied linguistics. To test the survey, we conducted a small pilot survey of thirteen diabetic patients who confirmed the clarity of the translated questionnaire: the Cronbach's alpha coefficient of the instrument was 0.84. The study used a five-point Likert scale in which five indicates a higher level of PCC. Scores for each subscale were calculated by summing the item scores within the subscale. In the current study, the Cronbach's alpha coefficient value was 0.97 for the overall PCC score and 0.84, 0.93, 0.92, and 0.94 for *effective communication, interest in patient agenda, empathy,* and *patient involvement in care*, respectively, indicating that the internal consistency is highly reliable.

The third section of the questionnaire included an open-ended question where participants were asked to describe their personal definition of patient involvement in care: “Based on your experience, what is the optimal role for patients to take in decision-making in care?”.

Data analysis

Quantitative data were downloaded from Qualtrics and entered into MS Excel and then exported to the Statistical Program for Social Sciences software (IBM SPSS Statistics) version 28 where all analyses were conducted. Summary statistics (frequencies, percentages, means, and standard deviations) were computed to describe the study sample. Analysis of variance (ANOVA) models were used to investigate whether participant age in three categories affected PCC subscales and overall PCC scores. Participants were divided into three groups according to their age (18-39, 40-54 and 55 years and above). All other demographic variables had two categories, and Student two-sample t-tests were used for these to investigate for differences in PCC scores between categories. Both ANOVA and Student t-tests were two-tailed. For these statistical tests, categories for each demographic variable were combined wherever possible to ensure a sample size of $\geq$ 30 in each group to ensure that normality assumptions of the test would be met (Kwak & Kim, 2017). However, we were unable to meet this condition for the nationality and treatment region variables due to small numbers in critical groups.

Pearson's correlation coefficient tests were used to determine the degree of correlation between the PCC subscales and overall PCC score. Significance was achieved if the p-value was <0.05 on any statistical tests. Analysis of the open-ended question responses aimed to provide information on how patients understood the practice of patient-centred care. The data analysis was led by the lead researcher (RAA) who is fluent in Arabic and English. Coding

was reviewed by the research team (JSM, RF and JB) together and then inductively coded based on the main themes raised in responses.

Ethical approval

The study was approved by the Human Research Ethics Committee of the University of Sydney [2021/530] and the Saudi Arabia Directorate of Health Affairs, Taif Institutional Review Board [HAP-02-T-067 number 596].

Results

Participant characteristics

A total of 116 participants completed the questionnaire. Demographic characteristics of participants are summarised in Table 1. Most participants were aged 18-39 (*N*=45, 38.8%) or 40-54 years (*N*=39, 33.6%), and half were male (*N*=60, 51.7%). The majority had an undergraduate degree or above (*N*=68, 58.6%) and roughly half were employed (*N*=61, 52.6%). Most were married (*N*=82, 70.7%), and a vast majority were of Saudi Arabian background (*N*= 104, 89.7%).

Roughly half of participants had type 2 diabetes (*N*=60, 51.5%) and the remainder had type 1. Over half of participants had lived with diabetes for 10 years or more (*N*= 65, 56.0%), and two-thirds did not report any other health conditions (*N*=77, 66.4%). Most participants received diabetes treatment in the Western region (*N*=97, 83.6%).

Table 1. Participant characteristics (N=116)

Characteristics	Counts (%)
Age	
18-39	45 (38.8)

40-54	39 (33.6)
55 +	32 (27.6)
Gender	
Female	56 (48.3)
Male	60 (51.7)
Education	
High school and lower	48 (41.4)
Undergraduate and more	68 (58.6)
Occupation	
Employed	61 (52.6)
Unemployed	55(47.4)
Marital Status	
Single	34 (29.3)
Married	82 (70.7)
Nationality	
Saudi	104 (89.7)
Non-Saudi	12 (10.3)
Type of diabetes	
Type 1	56 (48.3)
Type 2	60 (51.7)
Duration of diabetes	
<10 years	51 (44.0)
≥10 years	65 (56.0)
Other health conditions reported	
Yes	39 (33.6)
No	77 (66.4)
Treatment region (Province)	
Western Region	97 (83.6)
Other regions	19 (16.4)

Total	*116 (100)*

Quantitative analysis

The mean of the overall score for PCC was 63.31 (standard deviation (SD)= 15.31), which is 79% of the maximum possible score of 80. Mean scores for each item and subscale are summarised in Table 2. The highest mean subscale scores were for *effective communication* and *interest in patient agenda* (16.4 and 16.0 respectively), and lowest for *patient involvement in care* and *empathy* (15.3 and 15.6 respectively).

Table 2. Descriptive statistics of the patient-centred care subscales (*N* = 116).

Statements	*Mean (SD)*
Effective communication	**16.39 (3.44)**
The health practitioner respected me personally	4.15 (0.99)
The health practitioner spoke with me in a quiet and nice tone	4.22 (1.00)
The health practitioner paid attention to what I was saying	3.99 (1.13)
I obtained clear information from the health practitioner	4.03 (1.08)
Interest in patient Agenda	**15.96 (4.05)**
The health practitioner was interested in my feeling about my current health status	4.11 (1.12)
The health practitioner was interested in the information I know about my disease or the diagnosis	3.96 (1.17)
The health practitioner was interested in what I want from care.	3.97 (1.10)
The health practitioner was interested in what I expected from care	3.91 (1.08)
Empathy	**15.64 (4.11)**
The health practitioner took my feelings into consideration	4.04 (1.11)
The health practitioner was able to listen to me	4.09 (1.12)
The health practitioner was able to put him/herself in my place	3.49 (1.25)

The presence of the health practitioner beside me and his examination creates confidence and security	4.01 (1.12)
Patient involvement in care	**15.33 (4.37)**
The health practitioner asked questions that allowed me to express my point of view	3.79 (1.18)
The health practitioner allocated for me a time for asking him questions and speaking about my disease	3.81 (1.19)
The health practitioner provided me with the opportunity to discuss "the things which I have to do let me share in making a decision concerning them together"	3.81 (1.24)
The health practitioner encouraged me and created optimism inside me	3.91 (1.15)
Overall PCC	63.31 (15.31)

Each of the four PCC subscales and the overall PCC score were significantly associated with each other, as measured by the Pearson's correlation coefficient tests ($p<0.01$ for all pairs). The most correlated pairs were a) *empathy* and *interest in the patient's agenda* subscales (r= 0.92), followed by b) *interest in the patient's agenda* and *effective communication* (r= 0.90) and c) *patient involvement in care* and *interest in the patient's agenda* (r= 0.90). This is shown in Table 3.

Table 3. Pearson's R correlation coefficients between patient-centred care subscales and overall PCC score ($N = 116$)

Variables	**Effective communication**	**Interest in patient agenda**	**Empathy**	**Patient involvement in care**	**Overall PCC**
Effective communication		0.90*	0.90*	0.84*	0.94*
Interest in patient agenda			0.92*	0.90*	0.97*
Empathy				0. 90*	0.97*

Patient involvement in care	0.95*

***=P<0.01, PCC=patient-centred care**

Factors related to perceptions of patient-centred care

Table 4 summarises p-values from Student two-sample t-tests and ANOVA for testing for a difference in PCC scores between demographic groups. The only variable found to be significantly associated with overall PCC score or PCC subscales was treatment region. Patients treated in the Western region had significantly higher overall PCC score (mean 65 vs. 53, p<0.001) and higher scores for the subscales of *effective communication* (mean 16.9 vs. 14.0, p<0.001), *interest in patients agenda* (mean 16.6 vs. 12.8, P= .005), *empathy* (mean 16.2 vs. 13.3, P<.001) and *patient involvement in care* (mean 15.7 vs. 13.3, P= .03) compared with patients treated in other regions. This indicates that there might be a difference in the practice of PCC between the regions. No significant associations were found between other participant characteristics and PCC scores.

Table 4. Variation in patients' perceptions of patient-centred care by demographic factors. P values from ANOVA model for age and Student two-sample t-tests for all other characteristics

Characteristics		Effective communication		Interest in patient agenda		Empathy		Patient involvement		Overall PCC	
		Mean (SD)	P value	Mean (SD)	P value	Mean (SD)	P value	Mean (SD)	P value	Mean (SD)	P value
Age	18-39	16.7 (3.0)	0.45	16.7 (3.4)	0.12	16.2 (3.6)	0.25	15.7 (4.3)	0.64	65.3 (13.5)	0.30
	40-54	15.8 (3.9)		14.9 (4.7)		14.8 (4.7)		14.8 (4.8)		60.3 (17.6)	
	55 +	16.6 (3.5)		16.3 (3.8)		15.8 (4.0)		15.5 (3.9)		64.2 (14.6)	
Gender	Female	16.6 (3.6)	0.58	16.1(4.2)	0.70	15.8 (4.3)	0.61	15.9 (4.4)	0.21	64.4 (15.7)	0.47
	Male	16.2 (3.4)		15.8 (4.0)		15.5(4.0)		14.8 (4.3)		62.3 (15.0)	
Education	High school and lower	16.9 (3.3)	0.22	16.7 (3.6)	0.09	16.2 (3.7)	0.19	16.0 (4.1)	0.18	65.8 (14.0)	0.15
	Undergraduate and more	16.1 (3.6)		15.4(4.3)		15.2 (4.4)		14.9 (4.5)		61.6 (16.0)	
Occupation	Employed	16.3 (3.6)	0.84	15.8 (4.3)	0.70	15.6 (4.3)	0.90	15.4 (4.4)	0.90	63.1(16.0)	0.89
	Unemployed	16.5 (3.3)		16.1 (3.8)		15.7 (4.0)		15.3 (4.4)		63.5 (14.6)	

Marital status	Single	16.5 (3.8)	0.82	16.7(4.2)	0.24	16.0 (4.4)	0.51	15.6 (4.8)	0.72	64.74 (16.5)	0.52
	Married	16.3(3.3)		15.7 (4.0)		15.5 (4.0)		15.2 (4.2)		62.7 (14.9)	
Nationality	Saudi	16.2 (3.5)	0.09	15.8 (4.2)	0.28	15.5 (4.2)	0.18	15.1 (4.5)	0.18	62.6 (15.8)	0.16
	Non-Saudi	18.0(2.4)		17.2 (2.4)		17.2 (2.6)		16.9 (2.6)		69.3 (8.8)	
Type of diabetes	Type 1	16.5 (3.2)	0.82	16.4 (3.8)	0.28	15.8 (4.0)	0.68	15.5 (4.3)	0.65	64.2 (14.5)	0.57
	Type 2	16.3 (3.7)		15.8 (4.3)		15.5(4.2)		15.2 (4.5)		62.5 (16.1)	
Length of diabetes	9 years and lower	16.0 (3.9)	0.34	15.6 (4.1)	0.36	15.3 (4.4)	0.43	15.2 (4.1)	0.84	62.1 (15.9)	0.47
	10 years and more	16.7 (3.1)		16.3 (4.0)		15.9 (3.9)		15.4 (4.6)		64.2 (14.9)	
Other health conditions	Yes	16.4 (3.5)	0.99	15.7 (4.2)	0.69	15.6 (4.0)	0.89	15.3 (4.5)	0.90	63.0 (15.9)	0.86
	No/ NA	16.4 (3.5)		16.1(4.0)		15.7 (4.2)		15.4(4.3)		63.5 (15.3)	
Treatment regions (Province)	Western Region	16.9 (3.1)	<.001	16.6 (3.6)	0.005	16.2 (3.7)	<.001	15.7(4.1)	0.03	65.4 (13.7)	<.001
	Other regions	14.0(4.1)		12.8 (5.0)		12.68 (5.0)		13.3 (5.3)		52.8 (18.9)	

Qualitative thematic analysis

The qualitative component of the questionnaire in the form of the open-ended question identified two major themes:1) the patient's role in care and 2) the healthcare provider's role in healthcare.

Patient's role in care

When taken together, participant responses highlighted that patients generally perceived their optimal role in care to be mainly restricted to complying with their healthcare providers' instructions. For example:

> "The patient must follow the health practitioner's instructions and obtain the necessary health care and follow up his condition with the health practitioner … without neglect" (P36).

> "The role is to listen to him [healthcare provider] and do whatever is asked of you [patient] and avoid anything that can harm your health" (P9).

Others described their optimal role in care as being cooperative and sharing information with healthcare providers. For example, participants stated:

> "Being transparent and precise when answering the healthcare providers' questions and implementing the health provider care plan" (P7).

> "The patient must be cooperative, understanding and aware of his illness and what he [patient] must do towards himself and ... the health practitioner." (P33).

This indicates that participants did not have a clear understanding of the possible multiple active dimensions of their role in care but instead had a rather narrow understanding of themselves as passive recipients of care during consultations.

Health provider's role in care

In contrast to the passive role of patients described in responses, participants described the more active role of healthcare providers as providing enough time for patients and listening to patients. For example:

> "Listen to the patient with attention and do not make the patient wait long in the examination room" (P16)
>
> "The health provider listens to the patient" (P78)
>
> "Giving the patient enough time to explain his problem and do not write the prescription before I finish my explanation" (P20)

These quotes suggest that these patients had a simplistic and transactional understanding of the healthcare provider's role that does not extend to building a relationship for shared decision-making.

Discussion

This investigation was conducted to assess diabetic patients' experiences of PCC in their interactions with healthcare providers. Our quantitative findings indicate that patients generally perceived that they experienced PCC in their interactions with healthcare providers. However, the subscale for *patient involvement in care* received the lowest mean score, supporting the results of our qualitative analysis, which indicates a lack of patient awareness of the possibilities for a more active involvement in care. Patients described their

involvement in care as providing information and complying with healthcare provider instructions. This shows that patients were not aware of the extent to which they can be involved in care. Aljaffary et al. (2022) argued that the patients' level of awareness of shared decision-making processes influences patients' perceptions of their involvement in care. Patients' poor awareness of their role in care can be attributed to various causes. First, patients may be unaware of their rights to be informed of their health condition and treatment options (Almoajel, 2012). The nature of the power dynamic between patients and healthcare providers in Saudi society might also contribute to this finding. For example, patients' views of healthcare providers as authoritative figures contributes to patients being passive rather than active participants in care (Banaser et al., 2017). A study conducted to assess health provider communication skills during consultations within primary healthcare centres in the National Guard Hospital in Saudi Arabia found that 69% of healthcare providers rarely or sometimes involve patients in care, while 70% rarely or sometimes discuss the consultation goals with patients or pause to give patients the opportunity to interact (Al-Zahrani et al., 2015). The limited nature of interactions described in the qualitative data collected in our survey supports these results.

The *empathy* subscale received the second-lowest mean score of the four subscales. This result is not surprising given evidence from previous studies: in a review conducted to analyse the concept of empathy and its importance to the health profession, healthcare providers found it challenging to be empathetic towards patients due to organisational barriers, including lack of time to spend with patients and high patient workload on providers, which limit practitioners from building a therapeutic relationship with patients, thereby affecting the delivery of PCC (Moudatsou et al., 2020). This lack of time was reflected in some of the qualitative responses in our study. There is a need for healthcare organisations in Saudi Arabia to provide training to healthcare providers on how to develop and maintain

empathetic skills and practice these within the limited time they have available with their patients (Kerasidou et al., 2021; Moudatsou et al., 2020).

The item "*the health practitioner spoke with me in a quiet and nice tone*" and the related subscale *effective communication* received the highest scores from patients who participated in the study, indicating that health providers were clear and respectful during interactions. This finding is consistent with previous studies on PCC in other contexts which have showed that patients rate effective communication highly (Casu et al., 2019). In our study, the relatively high scores for effective communication might be due to the increasing recognition among providers of the importance of effective communication in facilitating patient involvement within the Middle Eastern region (Cheraghi et al., 2017; Joolaee et al., 2010; Rahman et al., 2019; Rassouli et al., 2020). For example, in Saudi Arabia the Ministry of Health has provided training programs that target non-Saudi healthcare providers to introduce them to local religious and cultural practices, thereby enabling culturally respectful communication (Alshammari et al., 2019; Van Bommel, 2011).

We found no significant variation in PCC scores based on patient age, gender, education level, occupation, marital status, nationality, type of diabetes, length of diabetes, or presence of other health conditions. An Italian study examining variation in PPIQ scores by patient characteristics reported differences based on patients' educational level, but similar to our study, no differences in scores between age or gender groups (Casu et al., 2019). Several other studies have also reported that patient demographic characteristics were not associated with their perception of PCC (Al-Tannir et al., 2017; Bakken et al., 2000; Goggins et al., 2014; Hany & Vatmasari, 2021). Only one of these studies reported mean PCC scores for patients: this study was based in Indonesia and reported an overall mean PCC score of 45.3 (SD 7.7) (Hany & Vatmasari, 2021), which is comparatively lower than the total mean PCC

score of 63.3 (SD 15.3) found in our study. However, without comparative studies between these two countries which interpret PCC in relation to their different cultural and healthcare contexts, it is difficult to interpret the significance of this difference.

We found that participants receiving treatment in the Western region reported higher levels of PCC compared with other regions. This may indicate different practices of PCC between regional areas and hospitals. However, this finding contradicts the results of a study by Aljaffary et al. (2022), which stated that patients living in the Eastern region of Saudi Arabia are more aware of shared decision-making than patients living in other regions of Saudi Arabia. Further studies are needed to investigate the association between patient perceptions of the provision of PCC and regional variables.

Study limitations

This study has two main limitations. First, the small sample size may restrict the generalisability of the study to diabetic patients within the wider community. In addition, a self-administered questionnaire was used in this study which increases the possibility of bias, such as social desirability bias. Despite these limitations, our study provides important insights into diabetic patients' experiences of their interactions with healthcare providers, which can be built upon in future research into patient involvement in care in Saudi Arabia. This research is part of a larger study that does seek to present both patient and healthcare provider perspectives.

Conclusion

This study found that diabetic patients in Saudi Arabia believed that they were experiencing PCC in their interactions with healthcare providers, but evidence was found of a lack of awareness of the full possibilities of PCC. Based on these results, an understanding of PCC

should be fostered further in healthcare in Saudi Arabia through patient education on their role in care, to improve their understanding of their possible active involvement in care. This would allow enhanced patient engagement, improved patient-provider communication, delivery of personalised care, and achievement of optimal healthcare outcomes. By prioritising PCC, the healthcare system can promote patient-centredness, improve patient satisfaction, and enhance the overall quality of care provided. There is limited literature on patients' perceptions of their interactions with healthcare providers in Saudi Arabia to which we can compare our results and limited international studies against which to directly compare our findings. Based on these remaining questions and the limitations presented above, further research is needed to understand the nature of patient-provider interactions in Saudi Arabia and in a comparative context.

CHAPTER 7

HEALTHCARE PROVIDERS' VIEWS ON THE PROVISION OF PATIENT-CENTERED CARE IN SAUDI ARABIA

Authors

Reeham Ahmed Alkhaibari, The University of Sydney, Centre for Disability Research and Policy, Sydney School of Health Sciences, Faculty of Medicine and Health, New South Wales, Australia. Taif University, Nursing Department, College of Applied and Medical Sciences, Taif, Saudi Arabia

Jennifer Smith-Merry, The University of Sydney, Centre for Disability Research and Policy, Sydney School of Health Sciences, Faculty of Medicine and Health, New South Wales, Australia

Rowena Forsyth, The University of Sydney, Cyberpsychology Research Group, Biomedical Informatics and Digital Health Theme, School of Medical Sciences, Faculty of Medicine and Health, New South Wales, Australia.

Jannah Baker, The University of Sydney, Health and Clinical Analytics group, School of Public Health, Faculty of Medicine and Health, New South Wales, Australia.

*Corresponding author: Reeham Ahmed Alkhaibari
Email: ralk6229@uni.sydney.edu.au
Telephone: +61 451943042
Sydney School of Health Sciences, The University of Sydney

Susan Wakil Health Building, Western Avenue, Camperdown, NSW, 2006, Australia

Authorship attribution statement

The article presented in this chapter is under review for publication in the *BMC Health Services Research Journal*; hence, presented in the format of the *BMC Health Services Research Journal*. I co-designed the study, co-analysed the data with my supervisory team, and wrote the drafts of the manuscript. The text in the chapter is identical to that in the manuscript submitted to the journal.

Name Reeham Ahmed Alkhaibari

Signed _____

Date _____

As the supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statement above is correct.

Name A/Pro Jennifer Smith-Merry

Signed_____

Date_____

Abstract

Background: Patient-centered care (PCC) is important to improve healthcare delivery. The Saudi government has been committed to improving the healthcare system and transforming the current system to patient-centered; however, there are barriers that might affect the implementation of PCC, including healthcare providers' knowledge and awareness about PCC. This study aimed to examine the understanding and implementation of PCC by healthcare providers working at King Abdulaziz Specialist Hospital in Saudi Arabia.

Method: Participants completed the Provider-Patient Relationship Questionnaire (PPRQ) to assess healthcare providers ability to implement PCC in their daily practice. Open-ended questions asked healthcare providers about their understanding of the concept of PCC and the reason for its implementation. Data were collected between January and September 2022

Results: The overall mean PCC score was 72/80 indicating that healthcare providers believe that they are effective in implementing PCC. Providers scored highest on *effective communication* and *interest in patient agenda* subscales (mean 18.5 and 18.1 respectively) and lowest on *empathy* and *patient involvement in care* subscales (mean 17.8 for each). No demographic factors were significantly associated with PPRQ scores, except for health profession: physicians scored higher for the empathy subscale than nurses (19.3 vs. 17.7, p 0.003). Responses to two open-ended questions identified two main themes 1) diversity in healthcare providers' conceptualization of PCC, with a generally narrow understanding of the concept of PCC and 2) supportive attitudes to PCC implementation with recognition of its benefits.

Conclusion: Quantitative findings indicate that healthcare providers perceive themselves as highly competent in practicing PCC. However, qualitative findings suggest that there is a lack

of understanding of the concept of PCC and that understanding of the standard dimensions of PCC may be impacted by the cultural context in Saudi Arabia.

Keywords: Patient-centered care, healthcare providers, Saudi Arabia

Background

The concept of patient-centered care (PCC) has become the cornerstone of many healthcare systems worldwide [1, 2] due to its promise to increase patient satisfaction and outcomes [3, 4] and to achieve high-quality of care [5-7]. Furthermore, this model prioritizes the ethical duties of respecting individuals' autonomy and opinions of individuals in the healthcare [8]. PCC is described as "providing care that is respectful and responsive to individual patient preferences, needs, values and ensuring that patients' values guide all clinical decisions" [9, p. 40]. There are three essential elements of a PCC model, including interacting with patients, partnership, and promotion of health [10]. Therefore, effective communication is essential to maintain the patient-provider relationship [11]. Despite the Saudi government's ambitious plan to transform the current healthcare system to a more patient-centered model of care [12, 13], there are possible challenges that would impact the effective delivery of PCC. For example, the Saudi healthcare system has been and continues to be dependent on expatriate healthcare providers, as there is a shortage of Saudi-born providers [14, 15]. According to recent data, only 40% of physicians and dentists within Saudi Arabia were of Saudi origin, while 57% of nurses were foreigners [16]. Most of the nurses were from India, the Philippines, Malaysia, Australia, North America, the United States, South Africa, and other parts of the Middle Eastern region [17, 18]. Healthcare providers from these countries have different cultural backgrounds and some may be unfamiliar with the Islamic religion or Saudi culture [17], which can affect healthcare practice and patient-provider interactions. Therefore, dependency on expatriate healthcare providers may contribute to patient dissatisfaction and poor quality of care [11]. For example, Alshammari, et al. [19] highlighted several barriers to patient communication with non-Saudi nurses, including language and cultural barriers and religious knowledge of healthcare providers. These barriers are likely to decrease patient satisfaction and may impact health outcomes.

Although limited studies have been conducted on healthcare providers perception of PCC, the available literature suggests that there is a challenge to the delivery of PCC due to the recognition and implementation of PCC by healthcare providers. For example, a study conducted to explore the views of healthcare providers regarding the implementation of shared decision-making in primary care centers in Saudi Arabia [2]. The findings revealed that many healthcare providers acknowledged the concept of shared decision-making and believed that their knowledge, education, and experience were crucial to its practice. However, some healthcare providers had limited knowledge of the concept. The study also identified several barriers that hindered the practice of shared decision-making, including lack of time, staff shortages, and lack of alternative treatment options to discuss with the patient [2].

Furthermore, there is evidence that healthcare providers in hospitals in Riyadh, Saudi Arabia, support patient involvement in care [20, 21]. Similarly, physicians working in primary care centers in Jeddah, Saudi Arabia, reported the value of sharing decision-making in improving patient satisfaction and adherence to medication [2]. Despite the recognized need for greater implementation of PCC in Saudi Arabia, it remains uncertain how willing healthcare providers are to practice PCC in their daily practice across Saudi Arabia and how well they recognize the concept of PCC. To address this knowledge gap, we sought to examine healthcare providers' understanding and implementation of PCC in Saudi Arabia.

Methods

Study design

This study aims to explore the perspectives of healthcare care providers with regards to their understanding and degree of implementation of PCC. The findings discussed in this publication are part of a larger study that encompasses both patients' and healthcare

providers' perceptions of PCC. The focus of this particular publication is to present the perceptions of healthcare providers.

Sample size

This study is part of a larger research project that aims to compare the perspectives of diabetic patients and healthcare providers regarding PCC. We hypothesized that there are similarities in patients' and healthcare providers' perceptions of PCC based on the findings of previous studies [21-23]. Therefore, two one-sided equal-variance t-tests were employed to calculate the required sample size to test for equivalence between groups. The analysis revealed that a sample size of 129 in each of the two groups (diabetic patients and healthcare providers) was required to establish a finding of equivalence between the groups with 80% power and a 5% significance level. However, due to the impact of Covid-19 and low response rates, this sample size was not able to be recruited. Recruitment was stopped after 9 months of data collection (1 January to 30 September 2022), with a total of 116 healthcare providers recruited into the study.

Participants and recruitment

Data were collected between January and September 2022. Recruitment for this study was initially restricted to healthcare providers working in diabetes centers of the King Abdulaziz Specialist Hospital. However, due to a lower response rate than expected and difficulties due to Covid-19-related restrictions, the recruitment was extended to include all healthcare providers working at King Abdulaziz Specialist Hospital during the study period. The hospital sent a letter of invitation to participate in a survey to healthcare providers on behalf of the research investigator. Participants were able to access the survey through a link that redirected them to the Qualtrics-hosted online survey. The questionnaire was administered in

English and all responses were anonymous. The completion of the questionnaire was considered to be informed consent to participate in the study.

Ethics approval

Ethics approval was obtained from the Human Research Ethics Committee of the University of Sydney [2021/530] and the Saudi Arabia Directorate of Health Affairs, Taif Institutional Review Board [HAP-02-T-067 number 596]. All methods were carried out in accordance with relevant guidelines and regulations.

Instruments

The survey contained three sections. The first section assessed the sociodemographic characteristics of participating providers and asked two open-ended questions: a) 'Explain the typical activities you carry out with diabetes patients on a regular working day' and b) 'How many minutes do you need with a typical diabetes patient to cover everything related to their care? Explain how you came to this figure." In the second section of the questionnaire, we further adapted a modified version of the validated Patient-Provider Relationship Questionnaire (PPRQ), which was adapted by Sultan, et al. [24] and was originally developed by Gremigni, et al. [25] to assist healthcare professionals in evaluating their own confidence when it comes to handling patient interactions in their daily work. We reworded certain items to enhance and improve the understanding of the participants (Appendix). In this study, we evaluated the internal consistency of our modified version of the questionnaire: the sixteen items in the questionnaire achieved a Cronbach's alpha coefficient of 0.94, indicating good internal consistency [26].

The PPRQ has four subscales; the first is *effective communication*, which assesses the perceived interpersonal skills of healthcare providers, including provision of clear

information and paying attention to the patient. The second subscale is *interest in the patient's agenda*, which examines the extent to which healthcare providers are interested in the patient's ideas, knowledge and care expectations. *Empathy* is the third subscale, which assesses the ability of healthcare providers to understand the emotions of patients. The last subscale is *patient involvement in care*, which examines the extent to which healthcare providers practice behaviors that support patient involvement, including allowing patients to talk and express their opinions [25]. A five-point Likert scale was used for each section of these subscales to assess the views of healthcare providers, where a score of 5 indicates a high provision of PCC.

The third section of the questionnaire focused on facilitators and barriers to the practice of PCC within the work environment, with both quantitative and qualitative aspects, based on the questions created by Sultan, et al. [24]. For the quantitative aspect, responses to eleven questions were scored using a five-point Likert scale ranging from 1= "strongly disagree" to 5= "strongly agree". We customized certain questions to ensure that it better addressed our research. This was followed by two open-ended questions: a) "What is your understanding of patient-centered care?" and b) "What would be the reasons for you to use patient-centered care?". The responses were analyzed following the five dimensions of PCC introduced by Mead and Bower [27], which include *biopsychosocial perspectives, patient as a unique individual, therapeutic alliance, sharing power and responsibility,* and *the doctor as a person*.

Data Analysis

Responses to all quantitative questions were entered as data into MS Excel and then imported into the Statistical Program for Social Sciences software (IBM SPSS Statistics) version 28, where all analyses were conducted. Descriptive statistics were calculated for responses to the

demographic and PCC subscales, including frequency and percentage (%) for demographic categories, mean (M) and standard deviation (SD) for the PCC subscales. Student's two-sample t tests and analysis of variance (ANOVA) models were used to examine for associations between participant demographic characteristics and PCC scores. Pearson's correlation coefficient (r) tests were used to examine associations between PCC subscales and the overall PCC score, and Spearman's rank order correlation (r_s) tests to examine relationships between work environment characteristics and PCC scores. All statistical tests were two-sided, and results considered statistically significant if their associated p-value was less than 0.05.

Responses to the four open-ended questions underwent qualitative analyses aimed at gaining an understanding of the perceptions and knowledge of healthcare providers around the concept and values of PCC. Responses were thoroughly examined, and related responses were assigned to a code, leading to the identification of the main themes and subthemes.

Results

Participant characteristics

Table 1 summarizes demographic characteristics of participating healthcare providers. A total of 116 providers participated in the study and completed the questionnaire. Most were aged below 35 years (62%) and females made up 90% of participants Most participants were non-Saudi (72%), the majority had a graduate degree or above (70%) and most had received their health education in non-Arab countries (55%).

The vast majority of participants were nurses (94%), and a third worked in the emergency department. Overall, 41% had been practicing their health profession for ten years or greater.

Over half had received workplace communication training (*N*= 73, 63%) and half of the participants reported spending 10-15 minutes with the patients on average (49%).

Healthcare providers' perceptions of PCC

The overall mean PCC score was 72.29, (SD) = 6.97) which is 90% of the maximum possible score of 80. Mean scores for each item and subscale are summarized in Table 2. The highest mean subscale scores were for *effective communication* and *interest in patient agenda* (18.5 and 18.1 respectively), and lowest for *empathy* and *patient involvement in care* (17.8 for each). Each of the four PCC subscales and the overall PCC score were significantly associated with each other, as measured by the Pearson's correlation coefficient tests ($p<0.01$ for all pairs). The most correlated pairs were a) *empathy* and *interest in the patient's agenda* subscales (r=0.77), followed by b) *empathy* and *patient involvement in care* (r=0.74) and c) *interest in the patient's agenda* and *patient involvement in care* (r=0.71). This is shown in Table 3.

Factors related to perceptions of patient-centered care

Table 4 summarizes p-values from Student two-sample t-tests and ANOVA models for a difference in PCC scores by participant characteristics. The only characteristic found to be significantly associated with overall PCC score or PCC subscales was healthcare profession. Physicians self-scored higher for the empathy subscale than nurses (mean 19.3 vs. 17.7, p 0.003). No significant associations were found between other participant characteristics and PCC scores.

Impact of work environmental factors on PCC provision

Results from Spearman's rank order correlation tests examining associations between work environmental factors and PCC scores are summarized in Table 5. Positive correlations were

found between the item *"Other doctors support high-quality patient- provider communication and facilitate them"* with the *patient involvement in care* subscale score (r_s=0.23, *P*= .02) and with the overall PCC score (r_s=0.21, *P*= .03). This indicates that perceptions of effective communication within the work environment may facilitate the provision of PCC. The item *"I find my job interesting"* was weakly correlated with the *empathy* subscale score (r_s= .19, P= .05). Negative correlations were found between the item "*I don't think that communication tasks help in clinical reasoning or improve the quality of medical care*" and the three subscales of *interest in the patient's agenda* (r_s=-0.20, *P*=.04) *empathy* (r_s= -.26, *P*=.01) and *patient involvement in care* (r_s =-.21, *P*=.03). This indicates that healthcare providers' perceptions of the role of communication would influence the practice of PCC. No other significant correlations were identified.

Consultation time preferences

Table 6 summarises responses to actual consultation length with diabetic patients (multichoice question with three categories) and preference for time needed to cover everything related to care (open-ended question). Overall, 24% of participants reported an average consultation length of 5-10 minutes, 49% reported 10-15 minutes and 27% reported 15 minutes or more. In contrast, the preference for time needed to cover everything related to care was much longer. Only 16% of practitioners responded that they preferred consultations of 5 or 10 minutes to cover everything, while 84% responded that they required 15 minutes or longer.

Qualitative Thematic Analysis

The qualitative component of the study identified two main themes: 1) healthcare providers' conceptualization of PCC and 2) healthcare providers' understanding of reasons for implementing PCC.

Healthcare provider conceptualization of PCC

The responses to the open-ended questions revealed variability in the correspondence between the perceptions of PCC of participating healthcare providers and the five dimensions of PCC, and therefore responses have been categorized as aligned or unaligned with these dimensions, as demonstrated by Fix et al. [28]. Well-aligned means that providers' conceptualization reflects these PCC dimensions well. Unaligned means that the conceptualization was not associated with or did not reflect these PCC dimensions well.

Well-aligned with the concept of PCC

Many participants conceptualized PCC according to the dimensions mentioned above. However, out of the five dimensions, only three dimensions were identified by the participants, as follows:

Biopsychosocial Perspectives

Healthcare providers reported that PCC views the patient beyond the disease and involves practices that integrate social, spiritual, and financial domains of life within care. For example, one physician stated that PCC involves: "taking the patient's preferences on the choice of medications… looking at social support… and his financial capability to afford medications". Another stated that " [healthcare] providers treat patients not only from a clinical perspective, but also from emotional, mental, spiritual, social, and financial perspective".

Patient as a unique individual

Healthcare providers perceived PCC as the provision of care according to patients' preferences. For example, one nurse stated that PCC involves "focusing care on the needs of

the individual and [their] preferences and values". Similarly, another nurse viewed it as "care that focusses on what patients need and tries to attend to all [patient] needs". Consideration of patient preferences in care was viewed as a way to achieve shared decision-making; for example, one physician noted that: "In patient-centered care, an individual's specific health needs and desired health outcomes are the main motivators to all healthcare decisions. " Other participants considered PCC as the patient's right to be fully informed and involved in care. For example, one physician stated that "Patient-centered care includes your [patient] right to comment, ask questions, and make complaints about your healthcare", while one nurse stated that "Patient-centered care gives the patient and family the rights and say in the decision-making process when planning care and treatment". This shows that healthcare providers believe that PCC values patient autonomy and participation in care by giving patients the opportunity to express their concerns.

Sharing power and responsibility

In this domain, participants described PCC as involving the patient alone or alongside family in care and decision-making. Some participants focused on the inclusion of both patients and family members. For example, one nurse stated that PCC is "individualized care that focusses on individual patient needs making sure that you [the healthcare provider] respect their [patients] values [and]… is family participation and involvement." Others added that PCC "helps to encourage active collaboration of care with the patient and... decision-making with family members" (nurse). Other participants described PCC to focus only on patient involvement. For example, one nurse described PCC as "Providing care to the patient…, understanding his [patient] needs, and ensuring that medical care and decisions are appropriate for the patient, with participation in decision-making". Another nurse noted that

PCC is "where healthcare providers should focus... on patients' [health] problems and involve them in all decisions regarding their health".

Only a few participants described PCC in terms of encouraging or empowering patients to play an active role in healthcare decision-making. One physician described it as a partnership between the patient and their healthcare providers: "Patients are partners with their healthcare providers", while others described PCC as encouraging patients to be active in care and to take responsibility for solving their health problems and supporting the rights of patients to be involved in care. A nurse stated that PCC is "care that encourages the patient and his relatives to share their thoughts and decisions with the healthcare team". Another added: "...it encourages patients to actively participate in the decision-making process over the period of their recovery".

In summary, it is evident that healthcare providers understand some of the key elements of PCC reported by Mead and Bower [27], specifically, the *biopsychosocial perspective, patient as a unique individual,* and *sharing power and responsibility*. However, the other two dimensions of PCC - *therapeutic alliance* and *the doctor as a person* - were not identified through the analysis, indicating that healthcare providers have a limited understanding of PCC.

Unaligned with the concept of PCC

In this category, the conceptualization of PCC expressed by healthcare providers was found to be poorly associated with the five dimensions of PCC. Participants defined PCC as a part of the provision of care. One participant stated that PCC is to "be with the patient when high or low blood sugar occurs by checking sugar" (nurse), and another commented that it is to "provide complete care to the patient" (nurse).

Some participants described PCC as synonymous with the process of providing good services to patients, for example, "providing better services to patients" (nurse) or "providing good nursing care" (nurse). Another participant defined PCC in terms of documentation practices and interactions between members of the healthcare team: "documenting the patient's disease course and treatment. Communication between the attending physicians and other healthcare providers who provide care to the patient. Continuous care of the patient" (nurse). Another viewed PCC as the process of gaining patient consent: "before giving any care to the patient... inform them regarding the care and procedure they [patients] are going to have and get consent accordingly" (nurse). These responses show a narrow understanding of PCC which focus on the practical aspects of care provision rather than on the broader principles of PCC. One participant focused on the role of providers with no mention of the patient's role when describing PCC: "The hospital management, medical and nonmedical staff are responsible for delivering patient-centered care, especially doctors and nurses" (nurse).

This quote indicates a lack of emphasis on patients' rights and involvement in care. There is a need for further education of healthcare providers around the dimensions of PCC to ensure a comprehensive and aligned approach to patient care. It is important to emphasize that a truly patient-centered approach recognizes patients as partners in care, and respects their values, preferences and rights.

Daily routine practices

In responses to the open-ended question "'Explain the typical activities you carry out with diabetes patients on a regular working day", we were interested in identifying examples of PCC that were part of the daily routine practices of healthcare providers. Physicians and nurses varied in their description of their interactions with patients based on their professional role. For example, a physician stated that his typical activities involved taking '"[the patient's]

full history and psychosocial history, examination, investigation, management, and sharing decisions with patients". Another similarly described: “taking full history, knowing the lifestyle and habits of the patient, and educating them on what to do to achieve the goals of a healthy lifestyle, make sure they take medication properly”. Nurses described practices in which they followed physicians’ orders without mentioning patient involvement or discussion with patients about care. For example, one nurse described their typical activities as: " vital signs are taken first, then physical examination by the doctor, discuss the patient's analyses, medications and doses, give him an appointment... and referral to the education clinic if he [the patient] needs [it]." Another reported "checking of glucose levels, administration of diabetes medication as per doctor order, monitoring of vital signs.". These examples reflect a routine practice where PCC is not immediately identifiable as part of the everyday interactions of healthcare providers.

Reasons for implementing PCC

In response to the open-ended question “What would be the reasons for you to use patient-centered care?”, respondents described benefits to patient care, teamwork and productivity to result from PCC implementation. Many participants believed that PCC would increase patient satisfaction and improve health outcomes. One nurse stated that reasons for implementing PCC included "to improve patient health outcomes... feeling of well-being physically as well as psychologically". Another nurse added that it would lead to patient satisfaction and improve healthcare provider practice, "patient satisfaction with the care provided, improving communication between the patient and caregivers, and thus improving the patient's condition and increasing the productivity of caregivers". Several participants also described that PCC implementation may reduce unnecessary procedures, e.g.," reduces unnecessary procedures… and improves patient health" (nurse). Furthermore, healthcare

providers viewed PCC implementation as important to improving quality of care: "[PCC] provides high-quality care to patients" (nurse). Another added that PCC "improves high-quality care and improves our [health care providers] teamwork" (nurse). These examples show that healthcare providers are generally supportive of PCC implementation and recognize several benefits to both patients and healthcare providers as a result of PCC implementation.

Discussion

This study was conducted to evaluate the implementation of PCC by healthcare providers. Our findings reveal that healthcare providers believe that they are effective in all aspects of PCC. For example, providers generally rated themselves as competent to practice effective communication. This may be a consequence of the recent interest in PCC in Saudi Arabia [12] and the expanded teaching of communication skills in medical schools [29]. This finding is consistent with the results of a study in Italy that healthcare providers perceived themselves to have effective interpersonal skills [25]. Effective communication plays a significant role in the process of patient involvement in care [2, 30]. It has been well described in the literature that effective communication improves the patient-provider relationship and improves patient outcomes such as patient satisfaction and adherence to treatment plans [31, 32].

In this current study, physicians self-scored higher on the empathy subscale compared with nurses. As this is a subjective measurement, it would be useful to compare these findings with ratings from patients. A previous study highlighted several factors that may contribute to a lack of empathy of healthcare providers, including high patient load, lack of time, and lack of empathy training [33]. It would be useful to examine whether any of these barriers exist in the context of healthcare provision in Saudi Arabia. For nursing staff in particular, this finding may be due to the current systematic challenges facing the nursing profession in

355 Saudi Arabia, including poor work conditions such as long work hours and rotating shifts
356 [34].

357 We found that the support of PCC practice by other healthcare providers within the work
358 environment is important to individual providers' motivation to implement PCC. Previous
359 literature has also emphasized the importance of the role of physicians and other healthcare
360 professionals in supporting and advocating for patients to facilitate PCC delivery [2, 35].

361 Our qualitative analysis explored providers' perceptions of PCC. Findings showed significant
362 variation in conceptualization of PCC. Many participants identified PCC in terms consistent
363 with the dimensions of PCC identified by Mead and Bower [27], which may be due to
364 training and education that they had received. However, others had a narrow view limited to
365 routine provision of care without mention of the role of the patient. This might be associated
366 with an authoritative perception of their role as a healthcare professional with the power to
367 make decisions [36]. Robinson, et al. [37] described a paternalistic approach to healthcare in
368 which providers deliver care without considering patient preferences. According to Banaser,
369 et al. [38], healthcare providers in Saudi Arabian culture are considered authoritative figures
370 who deserve respect and trust.

371 Our examination of reasons for implementing PCC revealed that providers believed that PCC
372 could improve health outcomes and quality of care for patients and improve productivity and
373 teamwork for providers. These reported benefits are consistent with the findings of previous
374 studies that PCC plays a significant role in improving patient health status, reducing
375 unnecessary procedures, improving quality of care, and improving healthcare provider
376 knowledge [2, 39, 40]. Several healthcare providers in this study also discussed family
377 involvement in relation to PCC. Previous studies have shown that family involvement in care

is a facilitator of the practice of PCC [39, 41, 42]. This finding might also be attributed to the embedded role of the family in healthcare within the Saudi Arabian culture [42, 43].

However, despite these positive perceptions of the potential benefits of PCC, implementation of PCC was not readily visible in the typical activities reported by providers. This may reflect a lack of clear understanding of the potential extent of PCC practices, as supported by the description of PCC by a number of participants as not well-aligned with the PCC dimensions described by Mead and Bower [27].

The findings presented here point to the need to understand PCC in relation to the cultural context of healthcare practice. The accounts of health practitioners show that cultural understandings of the authority of healthcare practitioners and the involvement of the family in care impact on the practice of PCC. Therefore, in order to implement PCC effectively, health care providers must recognize and respect the cultural background of patients. Recognizing and understanding the beliefs, values and practices of patients can help healthcare providers adapt their approach to PCC to meet cultural contexts and meet the needs and expectations of patients and their families.

The variation in perceptions of PCC among healthcare providers also indicates the need to integrate PCC into the curriculum for future healthcare providers and provide training programs within the healthcare organization. Given the discussion of the cultural context of PCC here, any such curriculum will need to be adapted to and implemented within the cultural context of Saudi Arabia. Although some healthcare providers understand the concept of PCC, there are some systematic barriers that could allow them to translate that knowledge into practice, such as time constraints, staff shortage, and patient overload [2] which, therefore, can impede the effective implementation of PCC. Therefore, to bridge the gap

between the knowledge and the effective delivery of PCC, ongoing education and training for healthcare providers is required.

This study had several limitations. First, the study was conducted in a single hospital and the small sample size may restrict the generalizability of the study. Furthermore, in this study, a self-administered questionnaire was used, which raises the potential for bias, including social desirability bias. Future work should expand on this by conducting observational studies to understand how and to what extent PCC is implemented in Saudi Arabia. Also, the study was originally aimed towards providers working within diabetic centres and questions were frames towards the care of diabetic patients, but due to difficulties with recruitment, inclusion criteria were expanded to include any healthcare providers within the hospital.

Conclusion

This study found that healthcare providers perceive themselves as highly competent in involving patients in patient-centered care on quantitative analysis. However, the findings of our qualitative analysis suggest that there is a lack of understanding of the concept of PCC and that this may be impacted by the cultural context in Saudi Arabia. This indicates that PCC education administered within curriculum and training programs must be cognizant of the cultural context of healthcare in Saudi Arabia. Future exploratory research is needed to understand how and to what extent PCC is practiced and to identify barriers that must be addressed to aid in effective PCC practice.

List of abbreviation

PCC: Patient-centered care; PPRQ: Patient-Provider Relationship Questionnaire; IBM Statistical Program for Social Sciences software; M: mean; SD: standard deviation (SD);

ANOVA: Analysis of variance; r: Pearson's correlation coefficient; r_s: Spearman's rank order correlation.

Declarations

Ethics approval and consent to participate:

Ethical approval was obtained from the University of Sydney and from the Saudi Arabia Directorate of Health Affairs Taif Institutional Review Board. The questionnaire was administered in English and all responses were anonymous. The completion of the questionnaire was considered to be informed consent to participate in the study.

Consent for publication: Not applicable

Availability of data and materials: The used datasets during the study and the analysis are available from the corresponding author.

Competing interests: The authors declare that they have no competing interests.

Funding: The lead author is supported by a PhD scholarship from Taif University

Authors' contributions: RAA, JSM, RF and JB were responsible for the study design and data analysis.: RAA, JSM, RF and JB contributed to the drafting of the article and the final approval of the article.

Acknowledgement

The authors acknowledge the King Abdulaziz Specialist Hospital for its cooperation. We extend our gratitude to all the participants who participated in this investigation. We also acknowledge the efforts of Abdulellah Al Thobaity and Amal Alsofiani for their support and participation in the data collection phase.

References

1. Epstein RMMD, Street RLP: **The Values and Value of Patient-Centered Care**. *Annals of family medicine* 2011, **9**(2):100-103.
2. Alsulamy N, Lee A, Thokala P: **Healthcare professionals' views on factors influencing shared decision-making in primary health care centres in Saudi Arabia: A qualitative study**. *Journal of Evaluation in Clinical Practice* 2022, **28**(2):235-246.
3. McMillan SS, Kendall E, Sav A, King MA, Whitty JA, Kelly F, Wheeler AJ: **Patient-centered approaches to health care: A systematic review of randomized controlled trials**. *Medical Care Research and Review* 2013, **70(6)**:567-596.
4. Rathert C, Wyrwich MD, Boren SA: **Patient-Centered Care and Outcomes: A Systematic Review of the Literature**. *Medical care research and review* 2013, **70**(4):351-379.
5. Frerichs W, Hahlweg P, Müller E, Adis C, Scholl I: **Shared Decision-Making in Oncology – A Qualitative Analysis of Healthcare Providers' Views on Current Practice**. *PLOS ONE* 2016, **11**(3):e0149789.
6. Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G: **Patient preferences for shared decisions: a systematic review**. *Patient education and counseling* 2012, **86**(1):9-18.
7. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, Thomson R, Barratt A, Barry M, Bernstein S: **Developing a quality criteria framework for patient decision aids: online international Delphi consensus process**. *Bmj* 2006, **333**(7565):417.
8. Millenson ML, Shapiro E, Greenhouse PK, DiGioia III AM: **Patient-and family-centered care: a systematic approach to better ethics and care**. *AMA journal of ethics* 2016, **18**(1):49-55.
9. Institute of Medicine: **Crossing the Quality Chasm: A New Health System for the 21st Century**Washington, D.C: National Academies Press; 2001.
10. Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, Ferrier K, Payne S: **Preferences of patients for patient centred approach to consultation in primary care: observational study**. *Bmj* 2001, **322**(7284):468.
11. Almutairi KM: **Culture and language differences as a barrier to provision of quality care by the health workforce in Saudi Arabia**. *Saudi medical journal* 2015, **36**(4):425.
12. Ahmad S, Singh J, Kamal MA, Shaikh ZM: **Person-centered care design with reference to healthcare outcomes in Saudi Arabia: an overview**. *Am J Civ Eng Archit* 2020, **8**(3):91-96.
13. Al-Sahli B, Eldali AM, Aljuaid M, Al-Surimi KM: **Person-Centered Care in a Tertiary Hospital Through Patient's Eyes: A Cross-Sectional Study**. *Patient preference and adherence* 2021, **15**:761 - 773.
14. Almalki M, FitzGerald G, Clark M: **Health care system in Saudi Arabia: an overview**. *Eastern Mediterranean Health Journal,* 2011, **17**(10):784-793.
15. Albejaidi F, Nair KS: **Building the health workforce: Saudi Arabia's challenges in achieving Vision 2030**. *The International journal of health planning and management* 2019, **34**(4):e1405-e1416.
16. **Statistical Yearbook 2018** Access date 17 March 2023 [https://www.moh.gov.sa/en/Ministry/Statistics/book/Documents/book-Statistics.pdf]

17. Almutairi A, McCarthy A: **A multicultural nursing workforce and cultural perspectives in Saudi Arabia: An overview**. *TheHealth* 2012, **3**(3):71-74.
18. Albougami AS, Alotaibi JS, Alsharari AF, Albagawi BS, Almazan J, Maniago J, EiRazkey J: **Cultural competence and perception of patient-centered care among non-Muslim expatriate nurses in Saudi Arabia: A cross sectional study**. *Pak J Med Health Sci* 2019, **13**(2):933-939.
19. Alshammari M, Duff J, Guilhermino M: **Barriers to nurse-patient communication in Saudi Arabia: an integrative review**. *BMC nursing* 2019, **18**(1):61-61.
20. Almudaimegh H, Alkanhal S, Alanazi F, Alquraishi N: **Assessment of Physicians' Perspective of Shared Decision Making in a Tertiary Care Hospital in Riyadh, Saudi Arabia**. *Global Journal on Quality and Safety in Healthcare* 2020, **3**(4):119-124.
21. Al-Tannir M, Algahtani F, Abu-Shaheen A, Al-Tannir S, Alfayyad I: **Patient experiences of engagement with care plans and healthcare professionals' perceptions of that engagement**. *BMC Health Services Research* 2017, **17**(1).
22. Medina-Artom TR, Adashi EY: **Patient-centered care in Israeli IVF units: divergent perceptions of patients and providers**. *Israel journal of health policy research* 2020, **9**(1):1-39.
23. Bodegård H, Helgesson G, Juth N, Olsson D, Lynøe N: **Challenges to patient centredness – a comparison of patient and doctor experiences from primary care**. *BMC Family Practice* 2019, **20**(1).
24. Sultan WIM, Sultan MIM, Crispim J: **Palestinian doctors' views on patient-centered care in hospitals**. *BMC health services research* 2018, **18**(1):766-766.
25. Gremigni P, Casu G, Sommaruga M: **Dealing with patients in healthcare: A self-assessment tool**. *Patient Education and Counseling* 2016, **99**(6):1046-1053.
26. Tavakol M, Dennick R: **Making sense of Cronbach's alpha**. *International Journal of Medical Education* 2011, **2**:53-55.
27. Mead N, Bower P: **Patient-centredness: a conceptual framework and review of the empirical literature**. *Social Science & Medicine* 2000, **51**(7):1087-1110.
28. Fix GM, VanDeusen Lukas C, Bolton RE, Hill JN, Mueller N, LaVela SL, Bokhour BG: **Patient-centred care is a way of doing things: How healthcare employees conceptualize patient-centred care**. *Health expectations : an international journal of public participation in health care and health policy* 2018, **21**(1):300-307.
29. Alotaibi FS, Alsaeedi A: **Attitudes of medical students toward communication skills learning in Western Saudi Arabia**. *Saudi medical journal* 2016, **37**(7):791.
30. Hoffmann TC, Lewis J, Maher CG: **Shared decision making should be an integral part of physiotherapy practice**. *Physiotherapy* 2020, **107**:43-49.
31. Kurtz SM: **Doctor-Patient Communication: Principles and Practices**. *Canadian Journal of Neurological Sciences / Journal Canadien des Sciences Neurologiques* 2002, **29**(S2):S23-S29.
32. Ha JF, Anat DS, Longnecker N: **Doctor-patient communication: a review**. *Ochsner Journal* 2010, **10**(1):38-43.
33. Moudatsou M, Stavropoulou A, Philalithis A, Koukouli S: **The Role of Empathy in Health and Social Care Professionals**. *Healthcare* 2020, **8**(1):26.
34. Lamadah SM, Sayed HY: **Challenges facing nursing profession in Saudi Arabia**. *Journal of Biology, Agriculture and Healthcare* 2014, **4**(7):20-25.
35. Reynolds A: **Patient-centered Care**. *Radiologic technology* 2009, **81**(2):133-147.
36. Shutzberg M: **The Doctor as Parent, Partner, Provider… or Comrade? Distribution of Power in Past and Present Models of the Doctor–Patient Relationship**. *Health Care Analysis* 2021, **29**(3):231-248.

37. Robinson JH, Callister LC, Berry JA, Dearing KA: **Patient-centered care and adherence: Definitions and applications to improve outcomes**. *Journal of the American Academy of Nurse Practitioners* 2008, **20**(12):600-607.
38. Banaser M, Stoddart K, Cunningham N: **A qualitative study of patient satisfaction in oncology wards setting in Saudi Arabia**. *Research and Reviews: Journal of Nursing and Health Sciences* 2017, **3**(3):85-97.
39. Obeidat R, Lally R: **Jordanian physicians' perceived barriers and facilitators to patient participation in treatment decision-making: An exploratory study**. *Indian journal of cancer* 2018, **55**(4):377-381.
40. Chung MC, Juang WC, Li YC: **Perceptions of shared decision making among health care professionals**. *Journal of Evaluation in Clinical Practice* 2019, **25**(6):1080-1087.
41. Rahman R, Matthews EB, Ahmad A, Rizvi SM, Salama U, Samad L, Khan M: **Perceptions of patient-centred care among providers and patients in the orthopaedic department of a tertiary care hospital in Karachi, Pakistan**. *Journal of evaluation in clinical practice* 2019, **25**(6):1160-1168.
42. Alkhaibari RA, Smith-Merry J, Forsyth R, Raymundo GM: **Patient-centered care in the Middle East and North African region: a systematic literature review**. *BMC Health Services Research* 2023, **23**(1).
43. Al-Shahri MZ: **Culturally sensitive caring for Saudi patients**. *Journal of Transcultural Nursing* 2002, **13**(2):133-138.

Table 1. Descriptive statistics of participant characteristics, N=116

Characteristics	Counts (%)
Age (years)	
<35	72 (62)
≥35	44 (38)
Gender	
Female	104 (90)
Male	12 (10)
Nationality	
Arab	33 (28)
Other nationality	83 (72)
Education	
Undergraduate degree and below	35 (30)
Graduate degree and above	81 (70)
Country of education	
Arab countries [1]	52 (45)
Other countries	64 (55)
Health profession	
Nurse	109 (94)
Physician	7 (6)
Specialty	
Nursing	88 (76)
Other [2]	28 (24)
Hospital departments	
Emergency department	39 (34)
Other departments	77 (66)
Years of practice	
< 5 years	32 (28)
5 -9 years	36 (31)
≥ 10 years	48 (41)

Received training in communication	
Never received training.	6 (5)
Received training in the university	37 (32)
Received training in the workplace	73 (63)
Knowledge of PCC	
I don't have or I have some knowledge of PCC	91 (78)
Extensive knowledge of PCC	25 (22)
Length of consultation (minutes)	
5 – 10	28 (24)
10 – 15	57 (49)
>15	*31 (27)*

[1] Arabs Countries = Saudi Arabia (N= 45), Egypt (N= 4), Egypt and Saudi Arabia (N= 1), Sudan (N= 1), and Syria (N= 1)

[2] Other = Not reported (N= 11); Hemodialysis (N= 3); Emergency (N= 3); Pediatric (N= 2); Gastroenterologist (N= 2); Medical and surgical (N= 2); Obstetrics and Genecology (N= 1); Cardiac (N= 1); Endocrine (N= 1); Operation (N= 1) and Midwife (N=1).

Table 2. Descriptive statistics of the patient-centered care subscales (N=116).

Statements	Mean (SD)
Effective communication	**18.50 (1.69)**
Provide clear information to the patient.	4.57 (0.54)
Speak to the patient in a calm and quiet tone.	4.59 (0.61)
Show respect to the patient as a person rather than a case.	4.69 (0.46)
Pay attention to what the patient says.	4.65 (0.51)
Interest in the patient agenda	**18.14 (1.98)**
Show interest in what the patient feels about their status.	4.61 (0.54)
Show interest in what the patient knows about their disease/prognosis.	4.52 (0.56)
Show interest in what the patient wants from care.	4.55 (0.58)
Show interest in what the patient expects from care in this hospital.	4.46 (0.63)
Empathy	**17.82 (2.12)**
Understand the emotions that the patient may have.	4.53 (0.59)
Check how illness affects the patient's daily life activities.	4.50 (0.61)
Put yourself in the "patient's place".	4.29 (0.84)
Inspire confidence and security when touching the patient or being nearby.	4.49 (0.63)
Patient involvement in care	**17.84 (2.17)**
Give the patient enough time to ask and talk about their disease.	4.55 (0.49)
Ask the patient questions that allow him to express their point of view.	4.47 (0.58)
Give the patient encouragement and transmit optimism.	4.44 (0.63)
Offer the patient the opportunity to discuss and share decision making.	4.38 (0.77)
Overall PCC	**72.29 (6.97)**

SD=standard deviation

Table 3. Pearson's R correlation coefficients between patient-centered care subscales and overall PCC score (*N*=116)

Variables	Effective communication	Interest in the patient agenda	Empathy	Patient involvement in care	Overall PCC
Effective communication		0.70*	0.60*	0.58*	0.81*
Interest in patient agenda			0.77*	0.71*	0.91*
Empathy				0.74*	0.80*
Patient involvement in care					0.80*
Overall PCC					

***P<0.01, PCC=patient-centered care**

Table 4. Associations between participant characteristics and their perceptions of PCC. P-values from Student's t-test

Variables		Effective communication		Interest in the patient agenda		Empathy		Patient involvement		Overall PCC	
		Mean (SD)	P	Mean (SD)	P	Mean (SD)	P	Mean (SD)	P	Mean (SD)	P
Age	< 35	18.4 (1.7)	.65	18.0 (2.1)	.45	17.7 (2.0)	.37	17.7 (2.0)	.42	71.9 (6.7)	.40
	≥ 35	18.6 (1.7)		18.3 (1.8)		18.0 (2.3)		18.0 (2.4)		73.0 (7.4)	
Gender	Female	18.5 (1.7)	.47	18.1 (2.0)	.84	17.8 (2.2)	.55	17.8 (2.2)	1.00	72.3 (7.1)	.95
	Male	18.2 (1.8)		18.3 (1.5)		18.2 (1.5)		17.8 (2.0)		72.4 (6.0)	
Nationality	Arabs	18.6 (1.7)	.67	18.5 (1.6)	.18	18.0 (1.7)	.39	17.8 (2.0)	.97	73.0 (6.0)	.44
	Other nationality	18.5 (1.7)		18.0 (2.1)		17.7 (2.3)		17.8 (2.3)		72.0 (7.4)	
Education	Undergraduate degree and below	18.9 (1.5)	.11	18.3 (2.1)	.60	17.8 (2.3)	.87	18.0 (2.3)	.66	72.9 (7.3)	.55
	Graduate degree and above	18.3 (1.8)		18.1 (1.9)		17.8 (2.0)		17.8 (2.1)		72.0 (6.9)	
Country of education	Arabs' countries	18.2 (1.9)	.13	18.1 (1.9)	.77	17.7 (2.3)	.45	17.7 (2.2)	.52	71.7 (7.3)	.38
	Other countries	18.7 (1.5)		18.2 (2.1)		18.0 (1.9)		18.0 (2.2)		72.8 (6.7)	
Health profession	Nurse	18.5 (1.7)	.57	18.1 (2.0)	.24	17.7 (2.1)	.003	17.8 (2.2)	.27	72.1 (7.1)	.16
	Physician	18.9 (1.2)		19.0 (1.4)		19.3 (1.0)		18.7 (1.7)		75.89 (4.1)	
Specialty	Nursing	18.5 (1.7)	.90	18.1 (2.0)	.44	17.8 (2.2)	.91	17.8 (2.2)	.72	72.1 (7.3)	.69
	Other	18.5 (1.6)		18.4 (1.7)		17.9 (1.9)		18.0 (2.0)		72.8 (5.9)	
Hospital departments	Emergency department	18.4 (1.8)	.60	17.9 (2.2)	.35	17.9 (2.1)	.85	17.9 (2.1)	.90	72.0 (7.2)	.77
	Other departments	18.6 (1.6)		18.3 (1.9)		17.8 (2.1)		17.8 (2.2)		72.4 (6.9)	
Knowledge of PCC	I don't have or I have some knowledge of PCC	18.5 (1.7)	.64	18.1 (1.9)	.69	17.8 (2.0)	.96	17.8 (2.2)	.83	72.2 (6.7)	.78
	I have extensive knowledge of PCC	18.6 (1.8)		18.3 (2.2)		17.8 (2.5)		17.9 (2.3)		72.6 (8.0)	

Table 4 continued. Associations between participant characteristics and their perceptions of patient-centered care, from analysis of variance models

Variables		Effective communication		Interest in the patient agenda		Empathy		Patient involvement		Overall PCC	
		Mean (SD)	P	Mean (SD)	P	Mean (SD)	P	Mean (SD)	P	Mean (SD)	P
Years of practice	< 5 years	18.2 (1.8)	.50	17.7 (2.5)	.34	17.4 (2.3)	.38	17.3 (2.1)	.08	70.7 (7.5)	.21
	5 -9 years	18.7 (1.6)		18.5 (1.6)		18.1 (1.7)		18.4 (1.7)		73.7 (5.8)	
	≥10 years	18.5 (1.7)		18.2 (1.8)		17.9 (2.3)		17.8 (2.5)		72.3 (7.4)	
Received training for communication	Never received training	19.2 (1.3)	.13	18.5 (2.0)	.67	18.8 (1.6)	.44	18.8 (1.8)	.51	75.3 (6.6)	.42
	Received training at the University	18.9 (1.5)		18.3 (1.9)		17.9 (1.9)		17.7 (2.3)		72.8 (6.8)	
	Received training at the workplace	18.3 (1.8)		18.0 (2.0)		17.7 (2.2)		17.8 (2.2)		71.8 (7.1)	
Length of consultation	5 – 10 minutes	18.6 (1.7)	.88	18.1 (1.9)	.88	17.6 (2.4)	.84	17.4 (2.8)	.34	71.7 (7.9)	.75
	10 – 15 minutes	18.4 (1.7)		18.1 (2.0)		17.8 (1.9)		17.8 (1.9)		72.2 (6.4)	
	15 +	18.5 (1.7)		18.3 (2.1)		18.0 (2.3)		18.3 (1.9)		73.1 (7.3)	

Table 5. Associations between work environment factors and healthcare provider PCC scores. P values and r_s coefficients from Spearman's rank order correlation tests

Statements	Effective communication		Interest in the patient agenda		Empathy		Patient involvement in care		Overall PCC	
	r_s	P	r_s	P	r_s	P	r_s	P	r_s	P
Hospital culture does not support effective patient-provider communication.	-.093	.34	-.12	.23	-.08	.41	-.14	.16	-.11	.27
I am overloaded with work and don't have enough time for a good interaction with patients	-.01	.93	.04	.72	-.03	.77	-.06	.56	-.02	.83
Other doctors support high-quality patient-provider communication and facilitate them.	.11	.27	.16	.09	.16	.10	.23*	.02	.21*	.03
Nurses cooperate positively with me to communicate with patients effectively.	.05	.61	.16	.11	.18	.07	.08	.43	.13	.17
In general, patients tend to give less information due to social consequences.	-.08	.42	.01	.92	-.03	.75	-.03	.73	-.03	.80
Most patients are not aware of their health status or their disease.	-.09	.38	-.06	.55	-.04	.71	-.11	.27	-.07	.45
Few patients judge communication tasks as valued or relevant to healthcare	-.02	.84	.10	.32	.11	.25	.02	.86	.07	.46
I don't think that communication tasks help in clinical reasoning or improve the quality of medical care.	-.18	.07	-.20*	.04	-.26**	.01	-.21*	.03	-.23*	.02
I feel satisfied with my work in this hospital.	-.05	.63	-.02	.82	.15	.13	.11	.25	.06	.51
I find my job interesting.	-.03	.73	-.02	.83	.19*	.05	.14	.14	.08	.40
I prefer to be formal rather than warm and friendly.	-.15	.12	-.08	.40	.01	.92	-.10	.30	-.08	.40

Table 6. Comparison of actual length of consultation (A) to time needed to cover everything related to patient care (B) for diabetic patients

Length of consultation (A)		
Time (minutes)	N	%
5-10	28	24.1
10-15	57	49.1
15 or more	31	26.7
Total	116	
Time needed (B)		
Time (minutes)	N	%
5	3	2.6
10	13	11.2
15	44	37.9
20	20	17.2
30	15	12.9
>30	7	6.0
Total	102*	

*14 responses were missing or invalid

Appendix

For each statement, please indicate how important you consider each action to be. How important is the following in your encounters with patients?

Statements	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Provide clear information to the patient.	○	○	○	○	○
Speak to the patient in a calm and quiet tone	○	○	○	○	○
Show respect to the patient as a person rather than a case.	○	○	○	○	○
Pay attention to what the patient says.	○	○	○	○	○
Show interest in what the patient feels about their status.	○	○	○	○	○
Show interest in what the patient knows about their disease/prognosis.	○	○	○	○	○
Show interest in what the patient wants from care.	○	○	○	○	○
Show interest in what the patient expects from care in this hospital.	○	○	○	○	○
Understand the emotions that the patient may have.	○	○	○	○	○

Check how illness affects the patient's daily life activities.	○	○	○	○	○
Put yourself in the "patient's place".	○	○	○	○	○
Inspire confidence and security when touching the patient or being nearby.	○	○	○	○	○
Give the patient enough time to ask and talk about their disease.	○	○	○	○	○
Ask the patient questions that allows the patient to express their point of view.	○	○	○	○	○
Give patients encouragement and transmit optimism.	○	○	○	○	○
Offer the patient opportunity to discuss and share decision making.	○	○	○	○	○

Working environment

For each statement, please indicate how much you agree or disagree with the statements provided.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Hospital culture does not support effective patient- provider communication	○	○	○	○	○
I am overloaded with work and don't have enough time for a good interaction with patients	○	○	○	○	○
Other doctors support high quality patient- provider communication and facilitate them.	○	○	○	○	○
Nurses cooperate positively with me to communicate with patients effectively.	○	○	○	○	○
In general, patients tend to give less information due to social consequences.	○	○	○	○	○
Most patients are not aware of their health status or their disease.	○	○	○	○	○
Few patients judge communication tasks as valued or relevant to healthcare	○	○	○	○	○
I don't think that communication tasks help in clinical reasoning or improve the quality of medical care.	○	○	○	○	○
I feel satisfied with my work in this hospital.	○	○	○	○	○
I find my job interesting.	○	○	○	○	○
I prefer to be formal rather than warm and friendly.	○	○	○	○	○

CHAPTER 8

DISCUSSION AND CONCLUSION

Introduction

This thesis has presented an academic investigation into the nature of patient-centred care in Saudi Arabia. The research utilised a systematic review of the literature to examine existing evidence on the practice of patient-centred care in the region of the Middle East and North Africa (MENA) alongside mixed methods data collection, which investigated patients' perceptions of their involvement in care, and quantitative research, which explored healthcare providers' perspectives on PCC provision. Through using these various methods and the inclusion of these different participant groups, a comprehensive understanding of how patients and healthcare providers perceive patient-centred care in Saudi Arabia was achieved. Consequently, the findings of this thesis are significant and are poised to contribute to the advancement of PCC in the Saudi Arabian healthcare system. In this chapter, the study findings are discussed in relation to the existing literature. This is followed by a discussion of the research contribution, recommendations, strengths and limitations and future directions for research following on from this study. Brief conclusions to the thesis are then made.

Overview of the findings

The focus of this thesis was to explore the nature of patient-centred care practice in Saudi Arabia. To achieve this objective, the study incorporated the perspectives of two groups, people living with diabetes and healthcare providers. The rationale behind choosing people living with diabetes was due to their need to regularly interact with the healthcare system due to the nature of their

health needs, which would therefore enable them to provide valuable insights into their interactions with healthcare providers and their involvement in the care process. Data to support this discussion were gained using a mixed method approach, namely systematic review, questionnaires, and semi-structured qualitative interviews of individuals living with diabetes.

Chapters 4, 5, 6 and 7 are the empirical chapters of this thesis. The systematic review conducted in Chapter 4 aimed to examine the existing evidence relating to patient-centred care and its practice within the MENA region. The findings of this review revealed a generally supportive position towards implementing PCC in the MENA region. However, the study also identified various contextual factors, particularly cultural influences, that play a significant role in shaping the practice of PCC within this region. Specifically, the role of the family (Baig et al., 2020; Obeidat & Lally, 2018; Rahman et al., 2019), the impact of the social standing of healthcare providers (Baig et al., 2020; Obeidat & Lally, 2018), and gender emerged as influential factors affecting the implementation of PCC. These findings shed light on the complex interplay between cultural norms and patient-centred care delivery. The systematic review served as a vital tool for establishing the existing knowledge and knowledge gaps in the research topic, refining the direction for this thesis, and guiding subsequent research efforts.

Chapter 5 presented an exploratory study that investigated the perceptions of diabetic patients about their involvement in care during interactions with healthcare providers in Saudi Arabia. The chapter reported that people living with diabetes in Saudi Arabia had limited knowledge of the concept of patient involvement. Patients exhibited a willingness to participate in decision-making processes, although in a minor role, but mainly relied on the expertise of their healthcare providers for decision-making.

Participants highlighted several barriers to PCC when interacting with healthcare providers. These barriers included patient-related factors (such as hesitation to ask questions), healthcare provider-related factors (such as perceived lack of empathy), and environmental factors (such as lack of continuity of care). Furthermore, the research indicated that the principles of Islamic culture influence the practice of patient involvement in care, necessitating the development of a patient-centred care model that aligns with the cultural values of Saudi Arabia.

Chapter 6 described a quantitative study of the experiences of diabetic patients when they interact with healthcare providers, based on a survey of patients. The findings indicate that, on average, patients reported experiencing PCC, as reflected by the overall mean PCC score of 63/80 (79%) on the Patient-Provider Interaction Questionnaire (Casu et al., 2019). However, it should be noted that the original instrument did not specify how the total score of PCC was rated, making it challenging to interpret whether the reported level of PCC was moderate or high. However, the responses to the open-ended question suggested that the patients had limited knowledge of their potential role in their own care. This chapter emphasises the importance of patient education, specifically focusing on PCC, as it has the possibility to enhance patients' knowledge regarding their potential role in their own care.

Finally, Chapter 7 described a quantitative study of the perspectives of healthcare providers on the provision of PCC. The study found that the overall mean PCC score was 72/80 (90%) on the Patient-Provider Relationship Questionnaire (Gremigni et al., 2016), indicating that healthcare providers believe they are effective in implementing PCC. However, the analysis of the open-ended responses revealed a significant variation among healthcare providers in describing the features and practices of PCC, suggesting a

lack of understanding of the concepts of PCC.

This thesis presents a unique contribution to healthcare research in Saudi Arabia, which is useful for understanding and improving practice. The study has provided an insight into opinions on patient-centred care from both patients and healthcare providers rather than looking at either group in isolation, thereby providing a more holistic understanding of current practice. Reliability of the results was achieved by comparing the study's findings with each other through a process of triangulation, which enhances the credibility and richness of the research results and conclusions (Hesse-Biber, 2010). Moreover, this research does not stop at mere documentation; it serves as a catalyst for change. It provides a gateway for proposing innovative policies and practices of patient-centred care by including different stakeholders. It also offers a new direction for future investigations in this field.

Discussing the Findings

This thesis provides empirical data on the implementation of PCC in Saudi Arabia and sheds light on the barriers associated with its implementation. The main themes of the findings are discussed in the following section.

Patients' and healthcare providers' perceptions of the concept of PCC

The importance of the PCC approach has been extensively explored in various research studies internationally. PCC is distinguished from non-patient-centred care by its establishment of a robust ethical and moral foundation, which compels healthcare providers to give paramount importance to patient interests and uphold patient autonomy. This, in turn, fosters a more meaningful patient-provider relationship (Epstein et al., 2010). Existing research indicates that PCC yields positive outcomes for

patients (Stewart et al., 2000), such as enhanced diabetes control (Jiang et al., 2021) and improved overall well-being (Arora, 2009; Kuipers et al., 2019). Furthermore, the successful adoption of the PCC approach has demonstrated its effectiveness in reducing the need for frequent diagnostic tests and referrals (Stewart et al., 2000), thereby enhancing patient safety and the quality of care (Jiang et al., 2021).

In the interviews conducted in Chapter 5, patients expressed their preference to be involved in their care. In Chapter 6, patients reported that they experienced PCC, while healthcare providers in Chapter 7 acknowledged the importance of PCC to achieve patient satisfaction and improve patients' overall well-being. This is aligned with previous studies conducted in Saudi Arabia. For example within a 2017 study conducted to investigate patients' experience of involvement with healthcare services and how healthcare providers perceive this involvement (Al-Tannir et al., 2017). 73% of patients and their families believed that healthcare providers involved them in decision-making processes regarding their care plan, and 80% felt like they were partners in the treatment plan. The study also found that one-third of healthcare providers believed that patient engagement could improve healthcare outcomes. This suggests that patients' perspectives are crucial in delivering patient-centred care and achieving better health outcomes. Healthcare providers need to engage patients in their care to promote patient involvement and enhance their knowledge regarding their potential role in their care. This approach can lead to improved patient satisfaction, better adherence to treatment plans, and, ultimately, better health outcomes.

However, the conceptualisation of ‘patient-centred care’ among both patients and providers varied greatly in this study. This research found that most patients were passive recipients when narrating their own role as patients (Chapter 6) and their

experiences when interacting with healthcare providers (Chapter 5). Patients voiced their support to be involved in care; however, their perspective on their role in care primarily revolved around adhering to healthcare provider instructions. On the other hand, in Chapter 7, the results showed that certain healthcare providers may have a limited understanding of PCC, as they fail to place emphasis on patients' rights and involvement in their own care. Other healthcare professionals viewed their interactions with patients as a routine aspect of their daily practices yet failed to fully recognise PCC as an integral component of their everyday interactions.

This limited conceptualisation of PCC by patients and healthcare providers might reflect a paternalistic approach to care in which healthcare providers make decisions on patients' behalf with the assumption that healthcare providers know best. This claim was recently supported by Woodman et al. (2022) who suggested that healthcare providers in Saudi Arabia had inadequate understanding of the possibilities of a more open doctor-patient relationship. This limited knowledge among healthcare providers in Saudi Arabia may be contribute to by the general perception of healthcare providers as having an authoritative position in society (Banaser et al., 2017). This perception is characterised by the assumption that their words and opinions are beyond question. Such a perception could have negative implications for patient- provider interactions, leading to a lack of patient involvement and poor communication. However, given the existing evidence on the benefits of adopting a PCC approach, this indicates the importance of educating and providing training for healthcare providers to adopt the skills needed to establish a partnership approach between patients and healthcare providers, exchange information, practice respect, and tailor care based on patient values and preferences.

Another contributing factor towards this lack of understanding between patients and

healthcare providers of the concept of PCC might be the lack of a comprehensive Middle East-oriented definition of PCC, which incorporates the cultural and religious principles of the region (Webair, 2020). Consideration of a definition of PCC that is based on the culture of the Middle East is therefore needed. There is a large and growing body of literature on PCC in Western countries (e.g. Rathert et al., 2013). However, it is important to note that research on the field of PCC in the Middle East is currently lacking, as described in Chapter 4 and within Alsulamy et al.'s (2021) work. Despite the cultural differences operating in the Middle East compared to Western countries, many studies in the Middle East use the Western definition of PCC with a clear absence of any adaptation of the PCC definition in relation to the culture of the Middle East (Webair, 2020).

The influence of culture on patient involvement in care has been widely acknowledged. Flores (2000) has highlighted that culture can have a significant impact on clinical care, including quality of health care and satisfaction with care. It also influences patient-provider interaction and the degree to which PCC is practised (Alkhaibari et al., 2023). Failure to consider culture may result in dissatisfaction with care, nonadherence, poor continuity of care, and miscommunication (Flores, 2000). The impact of culture on patient involvement in care has been evident in countries in the Middle East, such as Jordan (Obeidat & Khrais, 2016), Pakistan (Baig et al., 2020), and Saudi Arabia (Banaser et al., 2017). In this study (Chapter 5), cultural norms were viewed as potential barriers to patient-centred care. According to Matusitz and Spear (2015), patient perception of illness and well-being is intricately tied to cultural setting. For example, in the Middle East, religious practice and the support of the community can play a crucial role in shaping the approach to healing and enduring the journey of illness (Silbermann et al., 2013). Middle Eastern society leans more toward the collective approach where

familial involvement in decision-making is essential, contrasting with Western culture, which foregrounds/emphasises individualism (Silbermann & Hassan, 2011).

However, it is essential to recognise that the role of the family in care can act as a double- edged sword, as discussed in Chapter 4. Family involvement can serve as both a facilitator and a barrier to the decision-making process. This duality arises from the authoritative position held by families in certain cultures, such as Saudi Arabia, where they may override patient autonomy (Al-Shahri, 2002; Saleh Al Mutair et al., 2014). This was also observed in the interview results discussed in Chapter 5, in which a healthcare provider dismissed the patient from being involved in their care and communicated with their family instead. This attitude regarding family involvement could be rooted in the healthcare professional's perception that familial involvement constitutes a significant asset within patient care, warranting support and active participation to optimise patient outcomes (Al Mutair et al., 2014). This perspective aligns with previous literature in the Middle East, emphasising the importance and preference for family involvement in the decision-making process (Al Mutair et al., 2014; Alsulamy et al., 2021; Banaser et al., 2017). For example, in a study conducted to evaluate patients' and physicians' perspectives regarding patient involvement versus family involvement in the diagnostic disclosure and decision-making process in Saudi Arabia (Mobeireek et al., 2008), the study reported that the majority of patients expressed a preference for a family-centred model of care. The model of family-centred care is distinct from PCC because it emphasises the importance of the family as a whole in care, whereas PCC prioritises the autonomy of adult patients (Coyne et al., 2018).

Gender-based segregation is an integral aspect of Saudi culture, leading to restricted interactions between females and males (Almutairi & McCarthy, 2012). This cultural

norm influences patient preferences regarding the healthcare provider's gender. The systematic review in Chapter 4 highlighted that gender might have a significant influence on patient- provider interactions, potentially impacting the implementation of PCC. This was also commented on by a few patients in the interviews discussed in Chapter 5, who preferred to have same-gender healthcare providers. This finding supports previous research exploring the perspectives of healthcare providers and patients, identifying barriers and recommendations for providing culturally appropriate and patient-centred care for Muslim women in the United States (Hasnain et al., 2011). That study found that respecting patients' cultural and religious needs is essential. Failure to provide a female healthcare provider to conduct an intimate physical examination for a female patient is considered a violation by Muslim patients and their families, which clearly can thus adversely affect the relationship between the patient and the healthcare provider (Hasnain et al., 2011). Therefore, there is a need to accommodate patient values and beliefs regarding gender when providing care to build a therapeutic partnership between patients and healthcare providers.

It is also important to note the impact of patients' cultural perception of physicians as an authority in Saudi Arabia and the Middle East, which could negatively impact patient-provider relationships and, therefore, the practice of PCC. The concept of power distance represents the varying degrees of tolerance towards power inequality within different cultures (Rafiei et al., 2013). The results presented in Chapters 4 and 5 relating to the systematic review and patient interviews underscored how the healthcare provider-patient relationship in the MENA culture often mirrors a parent-child dynamic. This dynamic is characterised by values such as obedience and compliance towards the healthcare provider. The systematic review emphasised the perceptions of individuals living in the MENA region regarding healthcare providers as authority figures, consequently leading

to unequal power distribution. This finding aligns with studies conducted in Saudi Arabia reflecting a power imbalance between patients and healthcare providers (Alkhamees et al., 2023; Banaser et al., 2017). For example, a study in Saudi Arabia focused on investigating the influence of interpersonal elements of healthcare and socio-cultural interaction on patient satisfaction within the context of an oncology ward at the Saudi Regional Cancer Centre in Riyadh (Banaser et al., 2017).The findings of the study indicated that patients generally held the view that doctors were seen as authoritative figures deserving of respect, and their opinions were regarded as reliable and not to be contested. A similar perspective is observed in first-generation South Asian migrants living with chronic illnesses in Western countries (Vakil et al., 2023). Patients believe that they have limited control over their condition and that their healthcare providers are best qualified to provide care (Vakil et al., 2023). Power imbalance is a crucial obstacle to meaningful and productive patient-provider relationships (Scholz et al., 2017; Scholz et al., 2018). When there is a power imbalance, patients may feel hesitant to participate in their own care and ask questions, often preferring to be passive during interactions with healthcare providers (Cubaka et al., 2018; Cvetanovska et al., 2023). To manage power imbalances healthcare providers should prioritise creating a welcoming environment for patients. This would help to encourage patients to take an active role in their care, which can ultimately lead to better health outcomes. In addition, by emphasising the benefits of patient-provider collaboration, healthcare providers can ensure that patients remain involved and cooperative throughout their healthcare journey (Cubaka et al., 2018).

This discussion of the study results in relation to existing research shows the pressing need for a comprehensive definition of patient-centred care tailored specifically for the Middle Eastern and North African region - one that conscientiously considers cultural norms and religious factors. To bridge this gap, this thesis proposes a culturally tailored

definition of patient-centred care for the Middle Eastern and North African region. The development of such a definition followed the model used by the USA-based Picker Institute as the basis for their definition of PCC. The Picker Institute conducted a comprehensive study to examine USA patients' needs and concerns and to promote a model of care designed to make the experience of illness and hospitalisation more humane. The study included focus groups with patients and their family members, a literature review, and consultation with healthcare providers. The study identified seven dimensions of PCC, including "respect for patient's values, preferences, and expressed needs; coordination and integration of care; information, communication, and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; and transition and continuity of care" (Gerteis et al., 1993, p. xii). Through the systematic review, interviews, and questionnaires with healthcare providers and patients the findings of this thesis allowed for the development of a proposed definition of PCC more appropriate to the MENA region. The thesis findings highlighted the impact of cultural norms on the practice of PCC in the MENA region, specifically in Saudi Arabia, with a focus on the influence of family roles, healthcare providers' social status, and gender. Including these factors within a PCC definition that can then be used in the healthcare system can help improve patient-centred care in the region. This would facilitate the delivery of PCC that align with the cultural practices in Saudi Arabia, benefiting patients, families, and healthcare providers.

Based on the research findings, I propose this definition of PCC for the MENA region: "Establishing a 'therapeutic alliance' between patients, their family members, and healthcare providers to provide care that is tailored to the patient's individual needs and preferences while recognising cultural factors such as gender, religion, and family involvement that influence the patient-provider relationship." This definition includes the different elements of

PCC identified as essential elsewhere but adds those elements identified as essential within a MENA context. For example, therapeutic alliance has been described as a collaborative and dynamic process in which patients and healthcare providers jointly work towards achieving mutually agreed- upon goals through effective communication and shared decision-making (Horvath, 2000; Kim et al., 2008; Nancy Leopold et al., 1996). Adding the elements of family roles in patient care, healthcare providers' social status, and gender role would ensure that the care provided is tailored to the patients' needs and preferences.

The definition stresses the significance of acknowledging the crucial role that patients and their families have in their care. To provide exceptional care, it is imperative to include patients and their families as a part of the healthcare team in a cooperative and well- coordinated manner (Morley & Cashell, 2017). This not only helps in better understanding their needs but also ensures that their treatment plan aligns with their preferences and goals. Additionally, cultural factors play a significant role in how a patient perceives their care, and it's crucial for healthcare providers to be aware of and sensitive to these factors in order to provide the best possible care. Therefore, enacting this definition would ensure that patients receive personalised care that leads to positive outcomes for both patients and healthcare providers.

Patient and healthcare provider perception of PCC practice

Based on the quantitative findings from both patients (Chapter 6) and healthcare providers (Chapter 7), a notable disparity in the ratings of PCC between patients and providers was observed. Healthcare providers consistently rated all elements of PCC higher than the patients did, with mean scores of 72 out of 80 on the Patient-Provider Relationship Questionnaire (Gremigni et al., 2016) and 63 out of 80 on the Patient-Provider Interaction Questionnaire (Casu et al., 2019), respectively. This difference in

mean scores suggests that patients experienced some degree of patient-centred care during their interactions with healthcare providers, while healthcare providers perceived PCC as important when interacting with patients. It is worth noting that healthcare providers may tend to overrate their performance to present themselves as embracing PCC (Sidani et al., 2016). The results presented in this thesis showed that healthcare providers may be aware of the benefits associated with this approach for both patients and healthcare providers, as indicated in their responses to the open-ended question asking, "What would be the reasons for you to use patient-centred care?" (e.g., "*patient satisfaction with the care provided, improving communication between the patient and caregivers, and thus improving patient's condition and increasing the productivity of caregivers"*). These findings are consistent with a previous study conducted in Canada, which aimed to compare the perceptions of healthcare providers and patients regarding the practice of PCC. The study revealed that patients rated PCC lower than healthcare providers (Sidani et al., 2016).

The interpersonal skills of healthcare providers can either facilitate or hinder the delivery of patient-centred care. Effective communication is widely recognised as a vital component that healthcare providers must adopt to provide high-quality PCC (Robinson et al., 2008). Without effective communication, high-quality care is compromised as it is poorly targeted to patients' needs, leading to increased costs and undesirable patient outcomes (Ratna, 2019). In this study, both patients (Chapter 6) and healthcare providers (Chapter 7) rated effective communication the most highly among all PCC subscales. This indicates that both groups recognised the importance of effective communication as an essential element of PCC. Furthermore, the importance of effective communication with the patient was highlighted by patients in the interviews reported in Chapter 5 (e.g., *encouraging patients to communicate their concerns, actively listening to patients, and*

asking questions). Ha et al. (2010) suggested that for effective patient-provider communication, healthcare providers are required to possess certain skills, including active listening, empathy, and the use of open- ended questions.

Although healthcare providers acknowledge the importance of PCC, the findings in Chapter 7 also suggest that they may lack the knowledge to put it into practice and patients are therefore not recognising what they are doing as patient-centred. This discrepancy in valuing and acting with respect to patient-centred practices was also highlighted in a previous study conducted to investigate family-centred practice in Saudi Arabia from the perspective of paediatric nurses (Alabdulaziz et al., 2017). That study revealed that while nurses recognise the importance of family-centred care, they face challenges in integrating this model into their daily work. These challenges were related to language, communication, culture, and barriers related to hospital policies. It is worth noting that these challenges align with the barriers reported in chapters 4 and 5.

While healthcare providers perceived empathy as an important component of PCC, with a mean score of 17.8/20, Chapter 5 highlights the challenges patients face during their interaction with healthcare providers, such as their lack of empathy. This lack of empathy can manifest in several ways, such as the dismissal of patient concerns or inadequate encouragement for patient inquiries. There are several factors that contribute to the healthcare providers' lack of empathy towards their patients. One potential factor is the increased workload and time constraints faced by healthcare providers, which may limit their ability to provide high levels of empathy during patient interactions. Additionally, staff shortages within healthcare settings can further contribute to healthcare providers feeling overwhelmed and potentially impacting their ability to demonstrate empathy (Elayyan et al., 2018). These factors extend beyond the Saudi context (Alsulamy et al.,

2022) and persist within Western healthcare settings, as documented in published literature (Chung et al., 2019; Frerichs et al., 2016; Hofstede et al., 2013; Kim & Kim, 2023; Moore et al., 2017; Paiva et al., 2019; Wubben et al., 2021; Younas et al., 2016). For example, a study was conducted in the Netherlands to explore the views, experiences, and needs for shared decision-making in the intensive care unit (ICU), as perceived by ICU physicians, ICU nurses, former ICU patients and their close family members (Wubben et al., 2021). The study findings revealed that the decision-making process in the acute setting of the ICU presents significant challenges. The treatment approach in the ICU was characterised as being driven by a sense of urgency, primarily due to time constraints. Consequently, physicians often find themselves without adequate time for meaningful patient interaction to ensure that the treatment aligns with the patient's best interests and preferences (Wubben et al., 2021).

Another factor that may contribute to these differences is the narrow understanding of the concept of PCC among healthcare providers, as demonstrated in Chapter 7. This can be attributed to the lack of education and awareness among healthcare providers regarding the importance of patient involvement (Kim & Kim, 2023). Kuipers et al. (2021) suggest that inadequate education or training for healthcare providers to acquire new skills presents substantial barriers to effectively implementing the PCC. Similarly, Sultan et al. (2018) supports this suggestion, stating that doctors who were well-acquainted with PCC were more inclined to recognise its importance. Conversely, healthcare providers with limited knowledge of PCC and no prior training exhibit unfavourable perceptions of PCC (Sultan et al., 2018). Thus, it is crucial for healthcare providers to receive sufficient education and training to ensure the successful implementation of PCC.

To improve the implementation of PCC, the Ministry of Health and the Ministry of Education in Saudi Arabia should collaborate to develop educational and training programs focused on PCC and interpersonal skills for medical students and current healthcare providers. These programs should empower healthcare providers to adopt a more patient-centred approach and learn to communicate effectively with their patients (Epstein & Street Jr, 2011; Sultan et al., 2018). As identified in this study and the broader literature, this training should include modules that: 1) teach healthcare providers how to listen actively and empathetically to patients; 2) understand and respond to patients' concerns; 3) communicate clearly and effectively using plain language; 4) build trust and establish relationships with patients; 5) collaborate with patients to develop care plans that are tailored to their needs and preferences; 6) manage their expectations and address patient fears and anxieties; 7) provide emotional support to patients and their families. As per the proposed definition above, the training should also have a strong focus on cultural competence, as most healthcare providers in Saudi Arabia are from non-Saudi cultural backgrounds.

In addition to training healthcare providers, medical educational institutions in Saudi Arabia should proactively integrate patients as educators into their core curriculum in order to promote patient-centred approaches to care. This integration would allow students to gain a comprehensive understanding of the concept of PCC from the patient's point of view (Terrien & Hale, 2014). Patient educators can play several roles in medical education, including within clinical skills sessions, counselling, and physical examinations. They can offer constructive feedback throughout instructional sessions to students (Dijk et al., 2020). Patient educators can also share their healthcare-related experiences and personal life insights, mentoring healthcare providers and providing guidance and support throughout their training. They can participate in creating courses

related to their medical conditions or societal contexts and in the overarching competencies and community-based learning. They can be consulted to provide strategic input into establishing new departments within the medical school (Dijk et al., 2020). By incorporating patient instructors into formal medical education in Saudi Arabia, medical students can improve their communication skills, gain a deeper understanding of patient perspectives, increase their confidence in interacting with patients, and develop the competencies to deal effectively with ambiguity, emotions and stress. It would also have a lasting influence on developing technical skills, interpersonal skills, empathy, and the cultivation of individualised approaches to patient care (Spencer et al., 2011). Moreover, involving patients as educators in medical education can also prove valuable for patients themselves to manage their own health and enhance their confidence to express their needs during consultations (Dijk et al., 2020). Integrating such an approach into education would enhance the performance of future healthcare providers. For example, a study conducted in France examined residents' perceptions of the value of patient educators in general practice training program on their professional development (Aires et al., 2019). In this program, patient educators were actively involved in promoting a patient-centred approach by teaching residents a course on health democracy and collaborating with a physician teacher. The study found that residents held positive views of patient educators and acknowledged the benefits of incorporating patient perspectives into general practice. Residents believed that involving patient educators would improve the patient-care relationship and enhance their awareness of their own attitudes (Aires et al., 2019).

Factors that influence the practice of PCC

As demonstrated in Chapter 7, there is wide agreement among healthcare providers on the

importance of PCC for improved patient outcomes, such as increased patient satisfaction and the reduction of unnecessary medical procedures, among other benefits. However, there are significant factors that may impact the effective delivery of PCC in a healthcare environment. The attitude of healthcare providers towards patients during their interactions may influence the degree to which patients are involved in care. This was observed in the systematic review of the literature review in the MENA region related in Chapter 4. The review reported several barriers related to the actions of healthcare providers, including dismissing patient concerns, lack of eye contact with patients, and lack of knowledge about PCC. Similarly, patients in the interviews in Chapter 5 also reported barriers related to healthcare provider behaviours that impede their involvement in care. This included a lack of encouragement for patients to share their concerns and ask questions, and a lack of empathy. These findings are consistent with a recent systematic review conducted to identify the factors that influence shared decision-making (SDM) in the Eastern Mediterranean Region (Alsulamy et al., 2021). The study found that shared decision-making was influenced by various patient and healthcare provider characteristics, including their previous knowledge and experience of SDM and their preferences and perceptions of SDM.

Organisational factors were also found to impede the practice of PCC. The systematic review and qualitative findings reported in this thesis revealed several organisational barriers, including lack of continuity of care, lack of time during consultations, and long waiting times. This was also reported in the Alsulamy et al. (2021) study. That study highlighted that time constraints, continuity of care, and the availability of resources to support the implementation of PCC were contributing factors that influenced the practice of PCC.

Conceptual framework

Conceptual frameworks are helpful for making research findings more meaningful and comprehensible. They can help connect the findings together in a cohesive structure, which can make them more accessible and useful to others (Green, 2014; Polit & Beck, 2004). As there is no existing PCC framework specifically based on PCC in the context of Middle Eastern culture, I have derived one based on the findings of this study. The model is built upon the patient engagement continuum framework introduced by Carman et al. (2013), which outlines the various ways in which patients can participate in the healthcare system. This participation can vary from direct involvement, in which patients collaborate with healthcare providers to make decisions regarding their own care, to more extensive roles, such as co-leading roles to enhance hospital safety and quality improvement. Patients may also be involved in policymaking, contributing to the implementation and evaluation of health policy initiatives.

This is the first framework for PCC that is specifically tailored to the cultural norms of the Middle East and North Africa region. The framework was derived from the different components of the project data collection: the systematic literature review of published literature on the practice of PCC in MENA countries, semi-structured interviews with diabetic patients, and questionnaires distributed to patients and healthcare providers. Patients' and healthcare providers' responses, as well as the literature review, helped to understand the practice of PCC in MENA countries and underpinned the development of a proposed framework that focuses on patient-provider interaction and how it should be implemented. The Framework presented in Figure 1 below was developed based on the perception of diabetic patients and healthcare providers on patient-centred care.

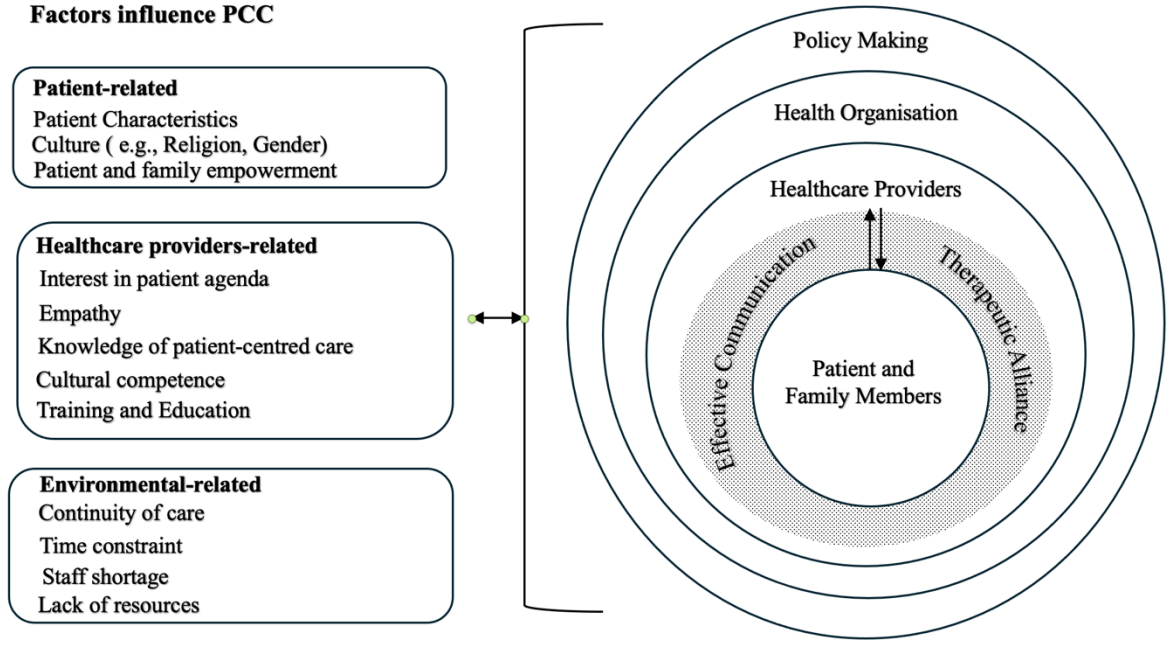

Figure 1. Framework of patient-centred care in the Middle East and North African Region

This model shows a two-way interaction between patients, family members, and healthcare providers. The Australian Commission on Safety and Quality in Health Care (2016) describe effective interaction as an exchange of information involves a dual-ended communication process that takes into account the patient's involvement in decision-making and care planning, utilising different forms of communication such as verbal, written and non-verbal cues. This communication is based on honesty and respect while also providing an opportunity for feedback and clarification. Effective interaction would help patients build trust and, therefore, a therapeutic patient-provider relationship. Evidence shows that effective interaction with patients can improve patients' understanding of medical information, well- being, and satisfaction (Ha et al., 2010). To effectively implement PCC, the different factors that influence the delivery of PCC must be practised as outlined in this framework. The different elements of the framework, examples, and how they apply to each of these are described below.

Patient and Family Members

Patient Characteristics: In Chapter 4, the systematic review revealed several contextual factors that play a significant role in shaping the practice of PCC within the MENA region. These factors include patient gender, education level, and health literacy, which were found to influence patients' perceptions of their involvement in care. Previous studies highlighted the role of patient characteristics, such as patients' low level of education and health literacy, as factors influencing patients' role to be active participants or passive recipients in care (Arora & McHorney, 2000; Benbassat et al., 1998; Flynn et al., 2006; Goggins et al., 2014; Hurst et al., 2022; Murray et al., 2007; Ryan & Sysko, 2007). A study conducted in Germany aimed to investigate the correlation between subjective health literacy skills, the perception of patient-centred communication and shared decision-making with patients' satisfaction with care provided by their general practitioner. The study found that patients who experienced that their general practitioner communicated information in a clear manner, had knowledge about their medical background, and allocated enough time for their appointments were more satisfied with their healthcare experience (Altin & Stock, 2016). Thus, during clinical interactions, healthcare providers must understand that not all patients want to be involved in care, and their education level and literacy may influence their preferences. Therefore, patient education and healthcare provider interpersonal skills are essential to facilitate patient involvement.

Culture: The role of culture is crucial in influencing patients' perceptions of health-related values, beliefs, and behaviour, as well as their approach towards diagnosis and treatment (Brown et al., 2016). It also impacts the level of trust patients and communities have towards healthcare providers (Brown et al., 2016; Kagawa-Singer et al., 2010). Both the systematic review and interviews with diabetic patients identified culture as a

significant factor that influences the way patients communicate with their healthcare providers. These factors include patient preferences for receiving care from same gender healthcare providers. This is not surprising in Saudi Arabia, where gender roles and societal norms can restrict interactions between males and females (Almutairi & McCarthy, 2012). Additionally, a patient's ethnicity, faith, and language can also play a significant role in their preferences to be involved in care. This highlights the importance of healthcare professionals being aware of cultural differences and adapting their communication style accordingly to provide effective and patient-centred care.

Patient and Family Empowerment: The involvement of families in patient care is crucial for providing patient-centred care (Ellers, 1993). This is especially important in countries located in the MENA region, where collectivist cultural values are prevalent (Ararat, 2006; Bouderbala et al., 2020; Rodríguez et al., 2011). These cultures are characterised by a strong attachment to family, extended family, or other close relationships, with loyalty to the family taking precedence over most other societal norms (Ararat, 2006). As highlighted in Chapter 4 of the systematic review, family involvement is perceived as a facilitator to deliver PCC, where decision-making priority is given to family members rather than individual patients. Thus, healthcare settings in these countries need to involve families in the decision-making process for patients, as they play a significant role in patient care.

Healthcare Providers

Interest in Patient Agenda: Gremigni et al. (2016) suggest that healthcare providers should demonstrate an interest in comprehending the patients' level of knowledge, emotional state, personal preferences, and expectations pertaining to their medical condition and the care they receive. Patient knowledge is fundamental to establishing partnerships in care (Pomey et al.,

2019). Individuals living with chronic illnesses develop significant knowledge about their conditions, and healthcare professionals should value and promote this knowledge (Karazivan et al., 2015). This knowledge was demonstrated in Chapter 5 where patients referenced their personal experiences and knowledge of their conditions and emphasised the importance of being active participants in decisions related to their healthcare. In addition, according to Singh et al. (2019), one important aspect of patient-centred care is the process of eliciting patient concerns and actively listening to them. Despite its significance, many healthcare providers struggle to successfully elicit the patient's agenda and often interrupt their discourse when they attempt to do so. In Chapter 7, healthcare providers rated interest in the patient's agenda highly, implying that they perceive it as a crucial aspect of their job. However, the systematic review in Chapter 4 and the patient interviews in Chapter 5 reported several barriers related to healthcare providers that suggest that healthcare providers may not always show interest in the patient's agenda to the level preferred by patients. These barriers include dismissing patient concerns and failing to encourage patients to share their thoughts or ask questions. Therefore, healthcare providers should make further efforts to prioritise the patient's agenda and actively listen to their concerns to ensure patient-centred care. To overcome the barriers in doing so, it is recommended that healthcare providers receive training and support to improve their communication skills and encourage patient engagement in their care.

Empathy: Empathy is an essential aspect of patient-centred care, and patients expect their healthcare providers to establish a compassionate and supportive relationship with them (Ferguson et al., 2013). However, the results presented in this thesis suggest a conflicting perception between healthcare providers and patients regarding empathy as a component to PCC. Although healthcare providers in Chapter 7 perceived empathy as an important component for practising patient-centred care, the results of the qualitative study reported

in Chapter 5 contradicted this result. Diabetic patients narrated their experiences with care and reported a lack of empathy from healthcare providers during their interactions, which negatively impacted their involvement in care. Therefore, it is essential for healthcare providers to understand the significance of empathy and make sure that they demonstrate empathy in their dealings with patients to offer effective and compassionate care.

Knowledge of PCC: It is crucial for healthcare providers to have a comprehensive understanding of PCC in order to effectively implement it. Based on the research conducted in Chapter 7, it was discovered that there are healthcare providers who may not fully comprehend what patient-centred care entails. A previous study has also demonstrated that healthcare providers who lack knowledge or understanding of PCC tend to hold negative views about it (Sultan et al., 2018). The lack of knowledge and understanding may impede the successful implementation of patient-centred care and hinder the overall quality of care provided to patients.

Cultural Competence: Cultural competence is a crucial aspect of healthcare that aims to improve the healthcare delivery. The primary objective of this approach is to achieve a balance in quality, promote fairness, and reduce disparities (Saha et al., 2008). According to Lin et al. (2017), cultural competence encompasses the capacity to recognise, value, and honour the cultural beliefs, customs, and expressed desires of patients seeking care. It involves an open-minded attitude towards individuals, families, and societies from diverse cultural backgrounds, along with the ability to apply this understanding into practical situations to improve the cultural appropriateness of healthcare services. The importance of culture in shaping the patient's perception of their role in healthcare is highlighted in Chapters 4 and 5. This suggests that healthcare providers must have a

comprehensive understanding of the diverse cultural and social factors that influence health and be aware of the health beliefs that are prevalent in every culture to provide effective care (Epner & Baile, 2012). This understanding can help healthcare providers deliver care that is culturally appropriate, respectful, and sensitive to the patients' needs.

Receiving Training and Education: Chapter 7's findings suggest that there are noticeable differences in how healthcare providers perceive PCC. To address this issue, it is crucial to integrate a PCC curriculum into the education of future healthcare providers and offer training to those already working in the field. Such education would lead to an improvement in the delivery of patient-centred care (Vijn et al., 2018). It is important to note that a lack of education and training can have a negative impact on the effective delivery of patient-centred care (Kuipers et al., 2021). Direct teaching and clinical experience are often necessary to acquire positive attitudes towards patient-centeredness (Haidet et al., 2005; McNair et al., 2016). Therefore, by prioritising education and training, healthcare providers can improve their ability to deliver excellent patient-centred care.

Healthcare Organisation

Chapters 4 and 5 have revealed several factors that impact the provision of PCC. These factors encompass lack of continuity of care, time constraints, long waiting time, high patient load, insufficient resources and infrastructure, staff shortage, and inadequate training, guidelines, and resources to promote PCC. Similarly, previous studies have reported that lack of staff, high patient-to-nurse ratio, heavy workload, and time constraints were identified as organizational factors influencing patient involvement (Alsulamy et al., 2021; Kwame & Petrucka, 2021; Ocloo et al., 2021). To overcome these obstacles, it is essential to enable patients to participate in organizational and policy decisions, drawing on their own

experiences in navigating the fragmented healthcare system (Pomey, Dumez, et al., 2019). This involvement can involve contributing to the design and implementation of quality improvement projects and co-leading initiatives with policymakers to influence healthcare policy (Carman et al., 2013).

Overall, the framework presented here addresses the lack of PCC frameworks in the MENA region. Unlike Western frameworks, this framework recognises the importance of culture as a crucial factor in PCC delivery. It emphasises the need for healthcare providers to be culturally sensitive in order to effectively deliver PCC. In addition, this framework acknowledges the significance of establishing a therapeutic alliance between patients and healthcare providers and provides a roadmap to guide the implementation of PCC. However, healthcare providers must consider all the factors outlined in this framework to successfully build a therapeutic relationship with patients and implement PCC. This model can be used by patients, healthcare providers, and policymakers to gain a better understanding of the patient-provider interaction. By identifying the factors that contribute to building therapeutic alliance, it can help ensure the effective implementation of patient-centred care. Patients can gain a better understanding of how to interact with their healthcare providers, while healthcare providers can use the model to improve their communication and relationship-building skills with patients. Policymakers can also use the model to inform healthcare policy decisions and promote patient-centred care at a broader level. The implementation of the model in the context of the current Saudi Arabian health system is discussed in the next section.

Implementing the model and definition in Saudi Arabia

To overcome the barriers identified in the thesis and successfully implement patient-centred care in Saudi Arabia, the Ministry of Health and health organisations in Saudi

Arabia must take strategic steps that approach the issue from multiple angles. In addition to better preparing the workforce via education, one of the most crucial measures is to reduce the patient load assigned to healthcare providers (Webair, 2020), which will allow them to allocate more time and attention to PCC practices. Moreover, healthcare providers must adopt plain and easily comprehensible language when interacting with patients, and avoid using complex medical terminology (Travaline et al., 2005; Webair, 2020). This practice will eliminate potential communication barriers (Warde et al., 2018), ensuring that patients can better understand their healthcare options and actively engage in decision-making processes (DeWalt et al., 2011; Nouri & Rudd, 2015; Ratna, 2019). Implementing educational initiatives aimed at patients is also essential (Webair, 2020). Patients need to be educated about the values and benefits of PCC. Raising awareness among patients about PCC and its inherent value can foster greater levels of patient involvement in their own care (Aljaffary et al., 2022; Pieterse et al., 2022), contributing to improved healthcare outcomes. These multifaceted strategies can collectively contribute to the successful implementation of PCC, yielding improved healthcare experiences and patient outcomes.

The New Model of Care in Saudi Arabia

The Ministry of Health designed 'New Models of Care' that 'aim to improve individuals' overall health and wellness, including their physical, mental, and social wellbeing. These models of care deliver 42 interventions across six systems of care - Keep Well, Safe Birth, Planned Care, Urgent Care, Chronic Conditions, and Last Phase (The Ministry of Health, 2019). This model has been designed around empowering individuals and increasing their personal value by improving the quality of treatment and care methods tailored to their unique needs (The Ministry of Health, 2019). However, a PCC model

goes beyond this new model by emphasising the importance of building a collaborative and therapeutic relationship between healthcare providers, patients, and their family members. This relationship ensures that all decisions made are based on the patient's preferences and needs, and that patients have the necessary knowledge and tools to be involved in their own care (Shaller, 2007).

Although the new model of care does not explicitly state patient involvement in care as part of the plan, it is important to note that involving patients in care is essential to demonstrating recognition of patients as active partners in care. Therefore, implementing this approach would allow patients to add their unique preferences, values, ideals, and goals to drive a patient-centred approach. Furthermore, the absence of the concept of patient involvement in the transformational plan does not mean that PCC is disregarded but raises the question of how the PCC principle can be fully embraced in Saudi Arabia. Even though the plan was intended to provide direction for employing and training healthcare professionals, the interpersonal skills of healthcare providers are an important area that the Ministry of Health and other health organisations need to focus on. This could be achieved by emphasising the importance of interpersonal skills in PCC delivery by promoting better patient-provider interaction and training. PCC supports the overall direction in the plan by enabling patients and their families to manage their health by empowering them with information and increasing their understanding of how to improve their health (Health Sector Transformation Program, 2021). As per the proposed framework, the PCC model should prioritise the interaction between patients and healthcare providers, with a strong emphasis on building a therapeutic relationship between them while closely considering the factors that impact this interaction. To achieve this, the integration of this framework with the new model of care is imperative for the Ministry of Health. Through the integration of this framework into training and

other systemic practices, healthcare providers will receive sufficient training, enabling them to develop the necessary skills and knowledge required to deliver PCC to patients effectively. Through this, patients will be empowered and better equipped to understand their roles in their own care and therefore participate in decision-making.

Implementation Strategies

The Ministry of Health is committed to developing and implementing policies that prioritise the health-related objectives set by the government (Mufti, 2000). As part of its recent Health Sector Transformation Program Delivery Plan, the health sector is focused on reforming the healthcare system around the needs of patients, and empowering them and their families with the knowledge and tools necessary to effectively manage their health (Health Sector Transformation Program, 2021). This approach includes seamlessly integrating the healthcare system, adopting a preventive approach, and providing optimal and personalised treatment for each individual. Therefore, it is crucial for the Ministry of Health to mandate the adoption of PCC in healthcare organisations as a policy.

To effectively implement a PCC focused health system, health organisations and the Ministry of Health must involve patients and other service users, including caregivers and relatives, in more meaningful and substantial ways (Bombard et al., 2018). This involves actively involving patients as partners or co-leaders in redesigning organisations and evaluating healthcare delivery (Bate & Robert, 2006; Berwick, 2009; Bombard et al., 2018; Carman et al., 2013). Patients should also be involved at a policy level through engaging with community leaders and policymakers to address community and social issues, influence healthcare policies, and determine resource allocation priorities (Carman et al., 2013).

Patients and their families have a unique perspective on what truly affects their ability to

remain healthy (Bechtel & Ness, 2010), and their involvement at all levels of healthcare can lead to a more comprehensive understanding of the public's preferences and what can lead to better outcomes (Mitton et al., 2009). Another strategy for the Ministry of Health to consider is improving and raising patient awareness of the significance of the principles of patient- centred care by establishing a patient advocacy group and fostering advocacy more generally. Barnsteiner (2014) writes that advocacy groups foster an environment where anything short of fully implementing PCC is considered inferior healthcare quality (Barnsteiner, 2014). The WHO defines advocacy in health as "…a combination of individual and social actions designed to gain political commitment, policy support, social acceptance and systems support for a particular health goal or programme" (World Health Organization, 1998, p. 5).

Zimmerman et al. (2005) have highlighted that patient advocacy organisations aim to increase public awareness and educate patients, provide assistance in accessing appropriate treatments and physicians who prioritise the well-being of patients, collaborate with medical professionals and other organisations in the development of new treatments, and support research towards more effective treatments. Advocates can work at a systemic or individual level. Brickley et al. (2021) argue that although PCC is based on the context in which it is implemented, including social experience and individual perspectives, a patient advocate working at an individual level can provide valuable insight into PCC due to their deeper understanding of the healthcare system compared with the patient. Providing patient-centred care also involves healthcare providers themselves advocating for their patients and ensuring they receive care that is effective and safe (Araki, 2019). In the context of the patient group explored in this current study, previous research has indicated that patient advocacy can be a useful tool to enhance diabetic patients' understanding of medication administration and lead to a

reduction in blood glucose levels (Rahem et al., 2019). However, the current healthcare system in Saudi Arabia lacks the provision of advocacy services for patients or their families (Almutairi, 2017), and this is therefore an area that requires improvement. Patient advocacy groups would be well placed to offer robust education, advocacy and support services tailored to patients, caregivers, and families (Rose, 2013). Therefore, the Saudi government should support the establishment of a patient advocacy organisation. This organisation could follow the example of the Australian Patient Association, a non-profit organisation that works to protect the rights and interests of patients and provide valuable information and assistance to patients while advocating for their needs (The Australian Patients Association, 2021). Another example is the Australian Patient Advocacy Alliance, which is an independent non-profit organisation that offers support to patients with complex and chronic conditions and advocates on their behalf. The organisation partners with national health organisations to gain an in-depth understanding of the actual needs of patients and ensure that the voices of patients are prioritised in crucial government decisions (Australian Patient Advocacy Alliance, 2022), thereby providing both individual and systemic advocacy.

Research contribution

The research findings of this study make a substantial contribution to the field of patient-centred care, particularly in relation to the Middle East and North Africa region. The study provides a comprehensive assessment of the current state of patient-centred care delivery and the knowledge and understanding held by the participants. It also sheds light on the influential factors affecting the implementation of PCC, including cultural and religious factors.

One of the most significant contributions of this research is the development of a patient-

centred conceptual framework rooted in MENA culture. This framework takes into account the cultural norms of the region and addresses a notable gap in the literature, which was the absence of a patient-centred care framework specific to the Middle East and North African region. The framework underscores the importance of considering regional values and beliefs when delivering patient-centred care. Moreover, this study enriches the existing knowledge base by providing insights into various aspects related to the current practice of patient- centred care, including the effectiveness of current PCC practices in the MENA region and, in particular, Saudi Arabia. It demonstrates the impact of cultural and religious factors on patient-provider interactions and identifies barriers and facilitators for the successful implementation of PCC. The study also highlights the urgency for healthcare providers to acquire effective interpersonal skills to successfully deliver PCC and actively engage patients in the decision-making process. Another important contribution has been made by proposing a comprehensive definition and framework for patient-centred care in the MENA region. This definition and framework were formed after a thorough review of the literature, mixed- methods data collection, and involving various participant groups in Saudi Arabia. The proposed definition and framework identify the crucial factors that influence the interaction between patients and healthcare providers in the MENA region and offer guidance on how to implement patient-centred care. This contribution holds significant value and can serve as a guiding tool for policymakers, healthcare providers, and researchers who are dedicated to improving the practice of patient-centred care in Saudi Arabia and the wider MENA region.

The use of mixed methods, including a systematic review and quantitative and qualitative research underpinning the development of the model and definition, is another significant contribution of this study in and of itself. It provides a deep

understanding of the nature of PCC delivery in Saudi Arabia and the broader MENA region.

Key recommendations

Based on the findings of this study as described above, several recommendations can be made to improve the delivery of patient-centred care in Saudi Arabia and the wider MENA region:

Ministry of Health

- To address the need for improved education for healthcare providers to implement PCC, the Ministry of Health and the Ministry of Education must work together to integrate patient involvement in medical education. This would ensure that healthcare students acquire these critical skills before joining the workforce.

- Patient and family involvement is a non-negotiable requirement in the planning and designing of patient-centred care policies to ensure that they are relevant and reflect patient interests. Patients and family members must be included in decision-making processes regarding their healthcare to ensure that policies accurately reflect their needs and preferences.

- The current Model of Care must undergo a thorough review involving diverse stakeholders, including patients and their family members, to explicitly consider PCC and guarantee that it accurately represents and meets the needs of patients. This will ensure that the delivery of patient-centred care is well-received by various participants in Saudi Arabia.

Hospital management

- Existing healthcare providers must receive ongoing training on effective communication and improve their interpersonal skills to facilitate the delivery of patient-centred care.
- Patients lack an understanding of PCC and its possibilities. Patients must therefore be provided with essential education to actively participate in their care.

Community

- The establishment of a patient advocacy group is imperative. This group can provide a platform for patients to voice their concerns and advocate for their rights at all levels of the healthcare system.

Strengths and Limitations

Strengths

This thesis has achieved a clear understanding of the practice of PCC in Saudi Arabia by capturing the perspectives of different participants, including diabetic patients and healthcare providers, and utilising a range of research methods. The systematic review of the literature on patient-centred care in the Middle East and North African region served to shape the direction of this thesis and embed it in the existing research. Another strength of this thesis is its use of different sampling techniques to recruit participants, which included purposive, snowballing, and convenience sampling methods, thereby including a varied and representative group of participants to enhance the validity and applicability of the findings. A major strength of this thesis is the deep exploration of participants' perceptions of PCC through using semi-structured interviews and employing open-ended questions in the surveys, leading to a comprehensive analysis of the subject matter. Lastly, this thesis proposed a definition and framework for patient-

centred care that aligns with the cultural values of the MENA region, which can contribute to the advancement of PCC in the healthcare system in the region.

Limitations

The studies in this thesis had several limitations. One of these is generalizability. The data demonstrate the perspective of diabetic patients living in Saudi Arabia. Findings might not be the same for other patients who have different health conditions. The research in Chapter 5 and Chapter 7 was conducted in one medical setting only; therefore, the findings may not be representative of different populations and settings. In addition, in the study of healthcare providers, most of the participants were nurses; therefore, the findings may reflect the perspective of the nurses but not those from other professions who may spend time with patients in different ways.

The quantitative studies in this research relied on self-report questionnaires completed by healthcare providers and patients, which introduces challenges in accurately verifying whether healthcare providers genuinely believe in the importance of PCC, as reported, and whether patients accurately reported their experiences with PCC (Demetriou et al., 2015). Healthcare providers' responses could have been influenced by social desirability bias, leading them to rate all elements of PCC as highly important due to their awareness of its value in the quality of healthcare (Demetriou et al., 2015). Similarly, patients might have been inclined to provide answers that they perceived as socially acceptable, potentially affecting the accuracy of their responses.

To address these limitations, future studies could consider employing additional validation methods, such as direct observation of healthcare providers' behaviours or conducting interviews with both healthcare providers and patients to gather more comprehensive data on their perspectives and experiences with PCC. These

complementary approaches could help corroborate the findings from self-reported questionnaires and provide a more comprehensive understanding of the perceptions and beliefs surrounding PCC in healthcare settings.

Future directions for research

This thesis has made a valuable contribution to the understanding of the delivery of patient- centred care in Saudi Arabia and has made practice and policy recommendations for changing healthcare practice in Saudi Arabia as described above. It also presents various considerations for future research in this field, not only in Saudi Arabia but for countries in the Middle East and North African region and for our understanding of PCC more generally. As such, it can serve as a valuable guide for conducting future research.

An area that requires more detailed exploration is the impact of culture on patient-centred care. Understanding how gender, family dynamics, and religion influence the practice of patient-centred care is essential for improving healthcare delivery in Saudi Arabia. This has also been a relevant finding for other similar cultural contexts, such as Malaysia, which is a developed nation that upholds comparable cultural values to Saudi Arabia, such as religious beliefs, family participation and a healthcare system that is more patient centred (Lee & Ng, 2017). In Chapter Seven, the study assessed healthcare providers' perceptions and understanding of the concept of patient-centred care. Replicating this research in different settings both within Saudi Arabia and beyond would allow for meaningful comparisons between institutions and regions, providing valuable insights into the adoption and effectiveness of patient-centred care. Furthermore, a follow-up study within the timeframe of three to five years is recommended to comprehensively evaluate the degree to which PCC has been effectively implemented in healthcare settings in Saudi Arabia and the MENA region.

This will provide valuable data for assessing the progress and impact of patient-centred care initiatives over time.

Another important direction for future research is investigating the contribution and role of educational institutions in patient-centred care curriculum development. Equipping future healthcare providers with the necessary skills to implement patient-centred care in their practice is vital. By exploring educational curricula and the perspectives of academic staff and students towards the practice of PCC in relation to changes in curricula, this research can significantly enhance the methods of teaching patient-centred care in Saudi educational institutions.

One limitation of this thesis is its focus on the perspectives of diabetic patients, leaving other clinical areas with significant patient-provider interactions underexplored. Future research should aim to address this gap and include marginalised groups, such as patient groups with mental illnesses, which have been relatively neglected in the existing literature within the Saudi Arabian context. These differences between patients and healthcare providers need to be further investigated using multi-methods approaches to gain a better understanding of both perspectives. While the quantitative findings provide valuable insights, a more comprehensive investigation using qualitative methods would allow for a deeper investigation of the underlying reasons behind these differences. A multi-methods approach would be valuable in exploring the factors that may contribute to the differences observed, including individual experiences, cultural influences, communication dynamics, and organisational factors (Sidani et al., 2016). It can also help identify potential areas for improvement in PCC and inform the development of targeted interventions and strategies.

In conclusion, this thesis has advanced our knowledge of patient-centred care in Saudi

Arabia and offers a roadmap for future research. By addressing the aforementioned limitations and exploring new research areas, further understanding and improvement in patient-centred care can be achieved in the region.

Conclusion

Given the paramount importance of implementing patient-centred care and the benefits associated with its implementation, it is crucial to thoroughly investigate the actual practices and perceptions of both patients and healthcare providers. Through the conduct of this study, I have successfully evidenced patient preferences for care and the shared understanding of PCC between patients and healthcare providers.

This thesis presented a comprehensive overview of the findings of a systematic review of existing literature and studies involving patients and healthcare providers. Although the quantitative results suggest that healthcare providers implement and deliver PCC effectively, responses to open-ended questions and patient interviews revealed a knowledge gap among both patients and healthcare providers on the concept of PCC. These findings clearly indicate that while there is some support for patient-centred care in Saudi Arabia, its practise remains limited. Furthermore, the findings of this study strongly suggest the need to engage the public in shaping healthcare priorities and establishing advocacy groups, which have the potential to improve PCC delivery in Saudi Arabia. By actively engaging the public and fostering collaborative efforts, we can further advance the implementation of patient-centred care, thus improving the quality of healthcare services provided in the country.

The purpose of this thesis was to contribute to the development of practice and policies guiding the practice of PCC in Saudi Arabia by examining patients' and healthcare providers' perceptions of the practice of PCC. This study used mixed methods by

surveying healthcare providers and individuals living with diabetes and interviewing the diabetic patients of key informants. The aim was to offer a comprehensive understanding of the current nature of PCC practice within the healthcare system in Saudi Arabia. Patient-centred care has grown to become the cornerstone of many high-quality healthcare systems worldwide. Recently, the government in Saudi Arabia has given strong attention to the matter of reforming the healthcare system and implementing a patient-centred care approach to support this. The effective implementation of PCC requires establishment of a therapeutic alliance and partnership between patients and healthcare providers. Gaining a better understanding from exploring the perception of patients and healthcare providers toward the practice of PCC in Saudi Arabia provides the Ministry of Health the opportunity to understand the current limitations and deficiencies in current practice to further enhance the implementation of the reforms.

In general, the understanding of the concept of PCC in Saudi Arabia seems to be limited, and therefore, there is a need to educate both patients and healthcare providers about PCC and its potential role in healthcare. The establishment of patient advocacy services would contribute to enhancing and prompting effective PCC. In addition, involving patients in planning and designing PCC policy is needed. The study also identified several factors that influence the practice of PCC. Barriers include family involvement, a low level of patient education, lack of patient involvement, lack of empathy on the part of providers, lack of continuity of care, lack of time for providers to spend with patients, and long wait times. On the other hand, facilitators include receiving emotional support from family members, effective communication, practitioners showing empathy and understanding towards patients, and health services allocating time to interact with patients. Data from this thesis shows that both patients and healthcare providers possess a limited

understanding of the concept of PCC and the patient's role in their own care.

Lastly, this thesis proposes a definition of MENA PCC and a framework that can guide future studies and practices. By providing a clear and comprehensive understanding of the concept, this research contributes to the growing body of literature on patient-centred care, particularly in the MENA region. With the proposed framework, healthcare providers and policymakers can implement PCC practices that are tailored and responsive to the unique needs of patients in the region. The findings of this research can help enhance the quality of healthcare services and improve patient outcomes in the MENA region, thus contributing to the development of evidence-based policies and guidelines for the delivery of PCC.

REFERENCES

Abdel-Tawab, N., & Roter, D. (2002). The relevance of client-centered communication to family planning settings in developing countries: Lessons from the Egyptian experience. *Social science & medicine (1982), 54*(9), 1357-1368. https://doi.org/10.1016/S0277-9536(01)00101-0 (Social Science & Medicine)

Abdelhadi, N., & Drach-Zahavy, A. (2012). Promoting patient care: work engagement as a mediator between ward service climate and patient-centred care: Promoting patient-centred care. *Journal of advanced nursing, 68*(6), 1276-1287. https://doi.org/10.1111/j.1365-2648.2011.05834.x

Abdelhafeez, S., Al-Swat, H., Babiker, S., Nasir, O., & Eisa, B. (2018, 01/01). The Prevalence of Diabetes Mellitus in Taif Region, Saudi Arabia during 2013-2014. *International Journal of Science and Research (IJSR)*. https://doi.org/10.21275/ART20202227

Abdulhadi, N., Al Shafaee, M., Freudenthal, S., Ostenson, C.-G., & Wahlström, R. (2007). Patient-provider interaction from the perspectives of type 2 diabetes patients in Muscat, Oman: a qualitative study. *BMC Health Services Research, 7*(1), 162-162. https://doi.org/10.1186/1472-6963-7-162

Abouqal, R., Phua, J., & Arabi, Y. M. (2018). Patient-physician relationship in specific cultural settings. *Intensive Care Medicine, 44*(5), 646-648. https://doi.org/10.1007/s00134-017-4960-4

Abubaker-Sharif, M., Shusted, C., Myers, P., & Myers, R. (2022). Primary Care Physician Perceptions of Shared Decision Making in Lung Cancer Screening. *Journal of cancer education, 37*(4), 1099-1107. https://doi.org/10.1007/s13187-020-01925-9

Ahmad, S., Singh, J., Kamal, M. A., & Shaikh, Z. M. (2020). Person-centered care design with reference to healthcare outcomes in Saudi Arabia: an overview. *Am J Civ Eng Archit, 8*(3), 91-96. https://doi.org/10.12691/ajcea-8-3-2

Ahmad, W., Krupat, E., Asma, Y., Fatima, N.-E., Attique, R., Mahmood, U., & Waqas, A. (2015). Attitudes of medical students in Lahore, Pakistan towards the doctor-patient relationship. *PeerJ (San Francisco, CA), 3*, e1050-e1050. https://doi.org/10.7717/peerj.1050

Ahmed, A. S. (1988). *Discovering Islam: Making Sense of Muslim History and Society*. Routledge. https://books.google.com.au/books?id=_3k9AAAAIAAJ

Aires, M. J., Gagnayre, R., Gross, O., Khau, C.-A., Haghighi, S., Mercier, A., Ruelle, Y., & Marchand, C. (2019). The Patient Teacher in General Practice Training: Perspectives of Residents. *Journal of Patient Experience, 6*(4), 287-295. https://doi.org/10.1177/2374373518803630

Akkafi, M., Sajadi, H. S., Sajadi, Z. S., & Krupat, E. (2019). Attitudes Toward Patient-Centered Care in the Mental Care Services in Isfahan, Iran. *Community mental health journal, 55*(3), 548-552. https://doi.org/10.1007/s10597-018-0357-2

Akturan, S., Kaya, Ç. A., Ünalan, P. C., & Akman, M. (2016). The effect of the BATHE interview technique on the empowerment of diabetic patients in primary care: A cluster randomised controlled study. *Primary care diabetes, 11*(2), 154-161. https://doi.org/10.1016/j.pcd.2016.12.003

Al Asmri, M., Almalki, M. J., Fitzgerald, G., & Clark, M. (2020). The public health care system and primary care services in Saudi Arabia: a system in transition. *Eastern Mediterranean health journal, 26*(4), 468-476. https://doi.org/10.26719/emhj.19.049

Al Faisal, W., Al Saleh, Y., & Sen, K. (2012). Syria: public health achievements and sanctions. *The Lancet, 379*(9833), 2241.

Al Mutair, A., Plummer, V., Paul O'Brien, A., & Clerehan, R. (2014). Attitudes of healthcare providers towards family involvement and presence in adult critical care units in S audi A rabia: a quantitative study. *Journal of clinical nursing, 23*(5-6), 744-755. https://doi.org/10.1111/jocn.12520

Al Yousuf, M., Akerele, T., & Al Mazrou, Y. (2002). Organization of the Saudi health system. *EMHJ-Eastern Mediterranean Health Journal,, 8*(4-5), 645-653. https://doi.org/10.26719/2002.8.4-5.645

Al-Hanawi, M. K., Khan, S. A., & Al-Borie, H. M. (2019). Healthcare human resource development in Saudi Arabia: emerging challenges and opportunities—a critical review. *Public health reviews, 40*(1), 1-16. https://doi.org/10.1186/s40985-019-0112-4

Al-Momani, M. (2010). Establishing family centred care in paediatric unit in Jordan: quality improvement. *Singapore Nursing Journal, 37*(2), 34-42.

Al-Sahli, B., Eldali, A. M., Aljuaid, M., & Al-Surimi, K. M. (2021b). Person-Centered Care in a Tertiary Hospital Through Patient's Eyes: A Cross-Sectional Study. *Patient preference and adherence, 15*, 761 - 773. https://doi.org/10.2147/PPA.S286237

Al-Shahri, M. Z. (2002). Culturally sensitive caring for Saudi patients. *Journal of transcultural nursing, 13*(2), 133-138. https://doi.org/10.1177/104365960201300206

Al-Sulaiman, A. A. (2000). SAUDI MEDICAL EDUCATION: CHALLENGES IN THE NEW MILLENNIUM. *Journal of Family and Community Medicine, 7*(1), 15-20. https://doi.org/10.4103/2230-8229.99211

Al-Tannir, M., Algahtani, F., Abu-Shaheen, A., Al-Tannir, S., & Alfayyad, I. (2017). Patient experiences of engagement with care plans and healthcare professionals' perceptions of that engagement. *BMC Health Services Research, 17*(1). https://doi.org/10.1186/s12913-017-2806-y

Al-Zahrani, B. S., Al-Misfer, M. F., & Al-Hazmi, A. M. (2015). Knowledge, attitude, practice and barriers of effective communication skills during medical consultation among general practitioners national guard primary health care center, Riyadh, Saudi Arabia. *Middle East Journal of Family Medicine,, 13*(4), 4-17. https://doi.org/10.5742/MEWFM.2015.92680

Alabdulaziz, H., & Cruz, J. P. (2020). Perceptions of female Saudi undergraduate nursing students toward family-centered care. *Nurse education today, 89*, 104421-104421. https://doi.org/10.1016/j.nedt.2020.104421

Alabdulaziz, H., Moss, C., & Copnell, B. (2017). Paediatric nurses' perceptions and practices of family-centred care in Saudi hospitals: A mixed methods study. *Int. J. Nurs. Stud., 69*, 66-77. https://doi.org/10.1016/j.ijnurstu.2017.01.011

Alameddine, M., AlGurg, R., Otaki, F., & Alsheikh-Ali, A. A. (2020). Physicians' perspective on shared decision-making in Dubai: a cross-sectional study. *Human resources for health, 18*(1), 33-39. https://doi.org/10.1186/s12960-020-00475-x

Alasiri, A. A., & Mohammed, V. (2022). Healthcare Transformation in Saudi Arabia: An Overview Since the Launch of Vision 2030. *Health Services Insights, 15*, 1-7. https://doi.org/10.1177/11786329221121214

Alatawi, A. D., Niessen, L. W., & Khan, J. A. (2020). Efficiency evaluation of public hospitals in Saudi Arabia: an application of data envelopment analysis. *BMJ open, 10*(1), e031924. https://doi.org/10.1136/bmjopen-2019-031924

Albejaidi, F., & Nair, K. S. (2019). Building the health workforce: Saudi Arabia's challenges in achieving Vision 2030. *The International journal of health planning and management, 34*(4), e1405-e1416. https://doi.org/10.1002/hpm.2861

Albejaidi, F. M. (2010). Healthcare system in Saudi Arabia: an analysis of structure, total quality management and future challenges. *Journal of Alternative Perspectives in the Social Sciences, 2*(2), 794-818.

Albougami, A. (2016). *The Relationship between Cultural Competence Levels and Perceptions of Patient-Centered Care among Filipino and Indian Expatriate Nurses working in the Saudi Arabian Healthcare Sector* ProQuest Dissertations Publishing]. Boston, Massachusetts

Albougami, A. S., Alotaibi, J. S., Alsharari, A. F., Albagawi, B. S., Almazan, J., Maniago, J., & EiRazkey, J. (2019). Cultural competence and perception of patient-centered care among non-Muslim expatriate nurses in Saudi Arabia: A cross sectional study. *Pak J Med Health Sci, 13*(2), 933-939.

Alden, D. L., Friend, J., Lee, P. Y., Lee, Y. K., Trevena, L., Ng, C. J., Kiatpongsan, S., Lim Abdullah, K., Tanaka, M., & Limpongsanurak, S. (2018). Who decides: me or we? Family involvement in medical decision making in eastern and western countries. *Medical Decision Making, 38*(1), 14-25. https://doi.org/10.1177/0272989X17715628

Alenazi, A. M., & Alqahtani, B. (2023). National and regional prevalence rates of hypertension in Saudi Arabia: descriptive analysis using national survey data. *Frontiers in Public Health, 11*, 1211. https://doi.org/10.3389/fpubh.2023.1092905

Alfahmi, M. Z. (2022). Patients' preference approach to overcome the moral implications of family-centred decisions in Saudi medical settings. *BMC Medical Ethics, 23*(1), 128. https://doi.org/10.1186/s12910-022-00868-8

Alhaiti, A. H., Senitan, M., Dator, W. L. T., Sankarapandian, C., Baghdadi, N. A., Jones, L. K., Da Costa, C., & Lenon, G. B. (2020). Adherence of Type 2 Diabetic Patients to Self-Care Activity: Tertiary Care Setting in Saudi Arabia [Article]. *Journal of Diabetes Research, 2020*, Article 4817637. https://doi.org/10.1155/2020/4817637

Alhalal, E., Alrashidi, L. M., & Alanazi, A. N. (2020). Predictors of patient-centered care provision among nurses in acute care setting. *Journal of nursing management, 28*(6), 1400-1409. https://doi.org/10.1111/jonm.13100

AlHaqwi, A., AlDrees, T., AlRumayyan, A., AlFarhan, A., & Badri, M. (2016). Patient's desire and preference for provision of information toward greater involvement in shared care. *Saudi journal of medicine and medical sciences, 4*(3), 172-177. https://doi.org/10.4103/1658-631X.188266

AlHaqwi, A. I., AlDrees, T. M., AlRumayyan, A., AlFarhan, A. I., Alotaibi, S. S., AlKhashan, H. I., & Badri, M. (2015). Shared clinical decision making: A Saudi Arabian perspective. *Saudi medical journal, 36*(12), 1472.

AlHaqwi, A. I., Amin, M. M., AlTulaihi, B. A., & Abolfotouh, M. A. (2023). Impact of Patient-Centered and Self-Care Education on Diabetes Control in a Family Practice Setting in Saudi Arabia. *International journal of environmental research and public health, 20*(2), 1109. https://www.mdpi.com/1660-4601/20/2/1109

Alharahsheh, H. H., & Pius, A. (2020). A review of key paradigms: Positivism VS interpretivism. *Global Academic Journal of Humanities and Social Sciences, 2*(3), 39-43. https://doi.org/10.36348/gajhss.2020.v02i03.001

Aljaffary, A., Alhuseini, M., Rayes, S. A., Alrawiai, S., Hariri, B., & Alumran, A. (2020). The OPTION Scale: Measuring Patients' Perceptions of Shared Decision-Making in the Kingdom of Saudi Arabia.(ORIGINAL RESEARCH). *Journal of multidisciplinary healthcare, 13*, 1337-1346. https://doi.org/10.2147/JMDH.S273340

Aljaffary, A., Alsheddi, F., Alzahrani, R., Alamoudi, S., Aljuwair, M., Alrawiai, S., Aljabri, D., Althumairi, A., Hariri, B., & Alumran, A. (2022). Shared Decision-Making: A Cross-Sectional Study Assessing Patients Awareness and Preferences in Saudi Arabia. *Patient Prefer Adherence, 16*, 1005-1015. https://doi.org/10.2147/PPA.S332638

Alkhaibari, R. A., Smith-Merry, J., Forsyth, R., & Raymundo, G. M. (2023). Patient-centered care in the Middle East and North African region: a systematic literature review. *BMC Health Services Research, 23*(1). https://doi.org/10.1186/s12913-023-09132-0

Alkhamees, M., Lea, J., Islam, M. S., Alasqah, I., Alzghaibi, H., Alharbi, M. F., Albejaidi, F., Mughal, Y. H., & Parker, V. (2023). A Qualitative Investigation of Factors Affecting Saudi Patients' Communication Experience with Non-Saudi Physicians in Saudi Arabia. *Healthcare journal, 11*(1), 118. https://doi.org/10.3390/healthcare11010118

Allen, M. (2017). *The SAGE Encyclopedia of Communication Research Methods*. https://doi.org/10.4135/9781483381411

Allende-Alonso, S., Bouza-Herrera, C., Rizvi, S., & Sautto-Vallejo, J. (2019). Big data and the central limit theorem: a statistical legend. *Revista Investigacion Operacional, 40*(1), 112-123.

Almalki, M., FitzGerald, G., & Clark, M. (2011). Health care system in Saudi Arabia: an overview. *Eastern Mediterranean Health Journal, , 17*(10), 784-793. https://doi.org/10.26719/2011.17.10.784

Almoajel, A. M. (2012). Hospitalized patients' awareness of their rights in Saudi governmental hospital. *Middle-East Journal of Scientific Research, 11*(3), 329-335.

Almudaimegh, H., Alkanhal, S., Alanazi, F., & Alquraishi, N. (2020). Assessment of Physicians' Perspective of Shared Decision Making in a Tertiary Care Hospital in Riyadh, Saudi Arabia. *Global Journal on Quality and Safety in Healthcare, 3*(4), 119-124. https://doi.org/10.36401/jqsh-20-8

Almutairi, A., & McCarthy, A. (2012). A multicultural nursing workforce and cultural perspectives in Saudi Arabia: An overview. *TheHealth, 3*(3), 71-74. https://eprints.qut.edu.au/57066/

Almutairi, A. G., & Al Shamsi, H. (2018). Healthcare system accessibility in the face of increasing privatisation in Saudi Arabia: lessons from Australia. *Global J Health Sci, 10*(7), 111-121. https://doi.org/10.5539/gjhs.v10n7p111

Almutairi, F. A. (2017). *Towards patient empowerment in Saudi healthcare: the place of a positive patient rights culture* (Publication Number 2589009) [Doctoral University of Canterbury]. New Zealand.

Almutairi, K. M. (2015). Culture and language differences as a barrier to provision of quality care by the health workforce in Saudi Arabia. *Saudi medical journal, 36*(4), 425. https://doi.org/10.15537/smj.2015.4.10133

Almutairi, K. M. (2015). Quality of Diabetes Management in Saudi Arabia: A Review of Existing Barriers. *Arch Iran Med, 18*(12), 816-821.

Alomari, N. A., Alshehry, B., Alenazi, A. H., Selaihem, A., AlQumaizi, K., Almishary, M., Elshinnawey, M. A., Alsuwayt, S. S., & AlHadlaq, R. K. (2021). Model of care knowledge among Riyadh First Health Cluster staff at the Ministry of Health, Saudi Arabia. *Journal of Family Medicine and Primary Care, 10*(8), 3094. https://doi.org/10.4103/jfmpc.jfmpc_405_21

Alotaibi, B. B. (2020). Self-Care Management Practices of Diabetic Patients Type 2 in Saudi Arabia. *Open Journal of Nursing, 10*(11), 1013-1025. https://doi.org/10.4236/ojn.2020.1011071

Alotaibi, F. S., & Alsaeedi, A. (2016). Attitudes of medical students toward communication skills learning in Western Saudi Arabia. *Saudi medical journal, 37*(7), 791. https://doi.org/10.15537/smj.2016.7.14331

Alraga, S. (2017). Comparative analysis of three different health systems Australian, Switzerland and Saudi Arabia. *Qual Prim Care, 25*(2), 94-100.

Alrowais, N. A., & Alyousefi, N. A. (2017). The prevalence extent of complementary and alternative medicine (CAM) use among Saudis. *Saudi Pharmaceutical Journal, 25*(3), 306-318. https://doi.org/10.1016/j.jsps.2016.09.009

Alshahrani, S., Magarey, J., & Kitson, A. (2018). Relatives' involvement in the care of patients in acute medical wards in two different countries—an ethnographic study. *Journal of clinical nursing, 27*(11-12), 2333-2345. https://doi.org/10.1111/jocn.14337

Alshammari, M., Duff, J., & Guilhermino, M. (2019). Barriers to nurse-patient communication in Saudi Arabia: an integrative review. *BMC Nursing, 18*(1), 61-61. https://doi.org/10.1186/s12912-019-0385-4

Alsulamy, N., Lee, A., & Thokala, P. (2022). Healthcare professionals' views on factors influencing shared decision-making in primary health care centres in Saudi Arabia: A qualitative study. *Journal of evaluation in clinical practice, 28*(2), 235-246. https://doi.org/10.1111/jep.13616

Alsulamy, N., Lee, A., Thokala, P., & Alessa, T. (2021). Views of stakeholders on factors influencing shared decision-making in the Eastern Mediterranean Region: a systematic review. *Eastern Mediterranean health journal, 27*(3), 300-311. https://doi.org/10.26719/emhj.20.139

Altin, S. V., & Stock, S. (2016). The impact of health literacy, patient-centered communication and shared decision-making on patients' satisfaction with care received in German primary care practices. *BMC Health Services Research, 16*(1), 1-10. https://doi.org/10.1186/s12913-016-1693-y

Amin, N., Cunningham, S. J., Jones, E. M., & Ryan, F. S. (2020). Investigating perceptions of patient-centred care in orthodontics. *Journal of Orthodontics, 47*(4), 320-329.

Aminaie, N., Mirlashari, J., Lehto, R., Lashkari, M., & Negarandeh, R. (2019). Iranian Cancer Patients Perceptions of Barriers to Participation in Decision-Making: Potential Impact on Patient-Centered Care. *Asia-Pacific journal of oncology nursing, 6*(4), 372-380. https://doi.org/10.4103/apjon.apjon_11_19

Andrew, S., & Halcomb, E. (2009). *Mixed methods research for nursing and the health sciences*. Wiley-Blackwell Pub.

Anney, V. N. (2014). Ensuring the quality of the findings of qualitative research: Looking at trustworthiness criteria.

Aoki, Y. (2020). Shared decision making for adults with severe mental illness: A concept analysis. *Japan Journal of Nursing Science, 17*(4), e12365. https://doi.org/10.1111/jjns.12365

APB Speakers. *Susan Frampton: Putting Patients First* [Video file]. https://www.youtube.com/watch?v=Ah86P63L5XU&t=176s

Araki, M. (2019). Patient centered care and professional nursing practices. *Journal of Biomedical Research and Clinical Investigation, 1*(1), 1004.

Ararat, M. (2006). Corporate Social Responsibility Across Middle East and North Africa. *SSRN Electronic Journal*. https://doi.org/10.2139/ssrn.1015925

Arora, N. K. (2009). Importance of patient-centered care in enhancing patient well-being: a cancer survivor's perspective. *Quality of Life Research, 18*(1), 1-4. https://doi.org/10.1007/s11136-008-9415-5

Arora, N. K., & McHorney, C. A. (2000). Patient preferences for medical decision making: who really wants to participate? *Medical care*, 335-341. https://doi.org/10.1097/00005650-200003000-00010

Artal, R., & Rubenfeld, S. (2017). Ethical issues in research. *Best Practice & Research Clinical Obstetrics & Gynaecology, 43*, 107-114. https://doi.org/10.1016/j.bpobgyn.2016.12.006

Aslam, F., Aftab, O., & Janjua, N. Z. (2005). Medical Decision Making: The Family–Doctor–Patient Triad. *PLoS Medicine, 2*(6), e129. https://doi.org/10.1371/journal.pmed.0020129

Australian Commission on Safety Quality in Health Care. (2011). *Patient-centred care: improving quality and safety through partnerships with patients and consumers*.

Australian Patient Advocacy Alliance. (2022). *Who we are*. Retrieved 23 December 2023 from https://patientadvocacyalliance.org.au/about/

Awasom, N. (2021). *Cultural Barriers in Healthcare Delivery from the Perspective of Patients* Uppsala University].

Babaei, S., & Abolhasani, S. (2020). Family's Supportive Behaviors in the Care of the Patient Admitted to the Cardiac Care Unit: A Qualitative Study. *J Caring Sci, 9*(2), 80-86. https://doi.org/10.34172/jcs.2020.012

Backman, W. D., Levine, S. A., Wenger, N. K., & Harold, J. G. (2020). Shared decision-making for older adults with cardiovascular disease. *Clinical cardiology (Mahwah, N.J.), 43*(2), 196-204. https://doi.org/10.1002/clc.23267

Baig, A. M., Humayaun, A., Mehmood, S., Akram, M. W., Raza, S. A., & Shakoori, T. (2020). Qualitative exploration of factors associated with shared decision-making in diabetes management: a health care provider's perspective. *International journal for quality in health care, 32*(7), 464-469. https://doi.org/10.1093/intqhc/mzaa073

Bakken, S., Holzemer, W. L., Brown, M.-A., Powell-Cope, G. M., Turner, J. G., Inouye, J., Nokes, K. M., & Corless, I. B. (2000). Relationships Between Perception of Engagement with Health Care Provider and Demographic Characteristics, Health Status, and Adherence to Therapeutic Regimen in Persons with HIV/AIDS. *AIDS Patient Care and STDs, 14*(4), 189-197. https://doi.org/10.1089/108729100317795

Balint, E. (1969). The possibilities of patient-centered medicine. *Journal of the Royal College of General Practitioners, 17*(82), 269-276.

Banaser, M., Stoddart, K., & Cunningham, N. (2017). A qualitative study of patient satisfaction in oncology wards setting in Saudi Arabia. *Research and Reviews: Journal of Nursing and Health Sciences, 3*(3), 85-97.

Barnsteiner, J. H. (2014). Overview and History of Person- and Family-Centered Care. In *Person- and family-centered care*. Sigma Theta Tau International Honor Society of Nursing.

Bastiaens, H., Van Royen, P., Pavlic, D. R., Raposo, V., & Baker, R. (2007). Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries. *Patient Education and Counseling, 68*(1), 33-42. https://doi.org/10.1016/j.pec.2007.03.025

Bate, P., & Robert, G. (2006). Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Quality and Safety in Health Care, 15*(5), 307-310. https://doi.org/10.1136/qshc.2005.016527

Bazm, S., Bazm, R., & Sardari, F. (2019). Growth of health literacy research activity in three Middle Eastern countries. *BMJ health & care informatics, 26*(1), e000027. https://doi.org/10.1136/bmjhci-2019-000027

Beach, M. C., & Inui, T. (2006). Relationship-centered Care. A Constructive Reframing. *Journal of General Internal Medicine, 21*(S1), S3-S8. https://doi.org/10.1111/j.1525-1497.2006.00302.x

Bechtel, C., & Ness, D. L. (2010). If you build it, will they come? Designing truly patient-centered health care. *Health Affairs, 29*(5), 914-920. https://doi.org/10.1377/hlthaff.2010.0305

Belcher, V. N., Fried, T. R., Agostini, J. V., & Tinetti, M. E. (2006). Views of older adults on patient participation in medication-related decision making. *Journal of General Internal Medicine, 21*(4), 298-303. https://doi.org/10.1111/j.1525-1497.2006.00329.x

Benbassat, J., Pilpel, D., & Tidhar, M. (1998). Patients' preferences for participation in clinical decision making: a review of published surveys. *Behavioral Medicine, 24*(2), 81-88. https://doi.org/10.1080/08964289809596384

Bentwich, M. E., Bokek-Cohen, Y. a., & Dickman, N. (2019). How figurative language may be related to formal care-givers' person-centred approach toward their patients with dementia. *Ageing and society, 39*(12), 2653-2670. https://doi.org/10.1017/S0144686X18000685

Bentwich, M. E., Dickman, N., Oberman, A., & Bokek-Cohen, Y. a. (2018). "I Treat Him as a Normal Patient": Unveiling the Normalization Coping Strategy Among Formal Caregivers of Persons With Dementia and Its Implications for Person-Centered Care. *Journal of transcultural nursing, 29*(5), 420-428. https://doi.org/10.1177/1043659617745137

Berghout, M., Van Exel, J., Leensvaart, L., & Cramm, J. M. (2015). Healthcare professionals' views on patient-centered care in hospitals. *BMC Health Services Research, 15*(1), 1-13. https://doi.org/10.1186/s12913-015-1049-z

Bergman, M. M. (2010). On concepts and paradigms in mixed methods research. *Journal of Mixed Methods Research, 4*(3), 171-175. https://doi.org/10.1177/1558689810376950

Bergman, M. M. (2011). The Good, the Bad, and the Ugly in Mixed Methods Research and Design. *Journal of Mixed Methods Research, 5*(4), 271-275. https://doi.org/10.1177/1558689811433236

Bertakis, K. D., & Azari, R. (2011). Patient-Centered Care is Associated with Decreased Health Care Utilization. *The Journal of the American Board of Family Medicine, 24*, 229 - 239. https://doi.org/10.3122/jabfm.2011.03.100170

Berwick, D. M. (2009). What 'Patient-Centered' Should Mean: Confessions Of An Extremist. *Health Affairs, 28*(4), w555. https://doi.org/10.1377/hlthaff.28.4.w555

Bodegård, H., Helgesson, G., Juth, N., Olsson, D., & Lynøe, N. (2019). Challenges to patient centredness – a comparison of patient and doctor experiences from primary care. *BMC Family Practice, 20*(1). https://doi.org/10.1186/s12875-019-0959-y

Boland, L., Graham, I. D., Légaré, F., Lewis, K., Jull, J., Shephard, A., Lawson, M. L., Davis, A., Yameogo, A., & Stacey, D. (2019). Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implementation Science, 14*, 1-25. https://doi.org/10.1186/s13012-018-0851-5

Bombard, Y., Baker, G. R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., Onate, K., Denis, J.-L., & Pomey, M.-P. (2018). Engaging patients to improve quality of care: a systematic review. *Implementation science : IS, 13*(1), 98-98. https://doi.org/10.1186/s13012-018-0784-z

Bouderbala, R., Eljammi, J., & Gherib, J. (2020). Relevance of Hofstede's model in identifying specific national cultural character: the case of a North African country.

Social Business, 10(3), 247-279. https://doi.org/10.1362/204440820X15929907056742

Brandt, A. M. (1978). Racism and research: the case of the Tuskegee Syphilis Study. *Hastings Center Report*, 21-29. https://doi.org/10.2307/3561468

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2021). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological* (pp. 57–71). American Psychological Association. https://doi.org/10.1037/13620-004

Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative research in sport, exercise and health, 13*(2), 201-216. https://doi.org/10.1080/2159676X.2019.1704846

Brickley, B., Williams, L. T., Morgan, M., Ross, A., Trigger, K., & Ball, L. (2021, 2021/03/20). Putting patients first: development of a patient advocate and general practitioner-informed model of patient-centred care. *BMC Health Services Research, 21*(1), 261. https://doi.org/10.1186/s12913-021-06273-y

Brody, D. S. (1980). The patient's role in clinical decision-making. *Annals of Internal Medicine, 93*(5), 718-722. https://doi.org/10.7326/0003-4819-93-5-718

Brown, K., Mace, S. E., Dietrich, A. M., Knazik, S., & Schamban, N. E. (2008). Patient and family–centred care for pediatric patients in the emergency department. *CJEM, 10*(01), 38-43. https://doi.org/10.1017/s1481803500009994

Brown, O., Ham-Baloyi, W. t., Rooyen, D. v., Aldous, C., & Marais, L. C. (2016, 2016/12/01). Culturally competent patient–provider communication in the management of cancer: An integrative literature review. *Global health action, 9*(1), 33208. https://doi.org/10.3402/gha.v9.33208

Brown, R. F., Butow, P. N., Henman, M., Dunn, S. M., Boyle, F., & Tattersall, M. H. (2002). Responding to the active and passive patient: flexibility is the key. *Health Expectations, 5*(3), 236-245.

Bunniss, S., & Kelly, D. R. (2010). Research paradigms in medical education research. *Medical education, 44*(4), 358-366. https://doi.org/10.1111/j.1365-2923.2009.03611.x

Byrne, A.-L., Baldwin, A., & Harvey, C. (2020). Whose centre is it anyway? Defining person-centred care in nursing: An integrative review. *PLOS ONE, 15*(3), e0229923. https://doi.org/10.1371/journal.pone.0229923

Carman, K. (2012). Implementation, engagement, and use: making health care more patient-centered, reliable, and safe. Plenary session remarks at: Agency for Healthcare Research and Quality 2012 Annual Conference,

Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Affairs, 32*(2), 223-231. https://doi.org/10.1377/hlthaff.2012.1133

Casu, G., Gremigni, P., & Sommaruga, M. (2019). The Patient-Professional Interaction Questionnaire (PPIQ) to assess patient centered care from the patient's perspective. *Patient Education and Counseling, 102*(1), 126-133. https://doi.org/10.1016/j.pec.2018.08.006

Centers for Disease Control and Prevention. (2022). *The U.S. Public Health Service Syphilis Study at Tuskegee*. Retrieved 20 March 2020 from https://www.cdc.gov/tuskegee/timeline.htm

CEPPP. (2024a). *About Us*. Retrieved 6 June 2024 from https://ceppp.ca/en/about-us/

CEPPP. (2024b). *Engaging Patients as Partners in Practice Improvement*. https://ceppp.ca/en/evaluation-toolkit/engaging-patients-as-partners-in-practice-improvement/

CEPPP. (2024c). *Evaluation Toolkit*. Retrieved 7 June 2024 from https://ceppp.ca/en/evaluation-toolkit/

CEPPP. (2024d). *Patient and Public Partnership Platform*. Retrieved 6 June 2024 from https://ceppp.ca/en/patient-and-public-partnership-platform/

Chaabna, K., Cheema, S., Abraham, A., Maisonneuve, P., Lowenfels, A. B., & Mamtani, R. (2021). The state of population health research performance in the Middle East and North Africa: a meta-research study. *Systematic reviews, 10*(1), 1-1. https://doi.org/10.1186/s13643-020-01552-x

Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Social science & medicine, 49*(5), 651-661. https://doi.org/10.1016/S0277-9536(99)00145-8

Charles, C., Gafni, A., & Whelan, T. (2004). Self-reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach. *Health Expectations, 7*(4), 338-348. https://doi.org/10.1111/j.1369-7625.2004.00299.x

Charmel, P. A., & Frampton, S. B. (2008). Building the business case for patient-centered care. *Healthcare financial management, 62*(3), 80-85.

Cheraghi, M. A., Esmaeili, M., & Salsali, M. (2017). Seeking Humanizing Care in Patient-Centered Care Process: A Grounded Theory Study. *Holistic nursing practice, 31*(6), 359-368. https://doi.org/10.1097/HNP.0000000000000233

Chewning, B., Bylund, C. L., Shah, B., Arora, N. K., Gueguen, J. A., & Makoul, G. (2012). Patient preferences for shared decisions: a systematic review. *Patient Education and Counseling, 86*(1), 9-18. https://doi.org/10.1016/j.pec.2011.02.004

Chipidza, F. E., Wallwork, R. S., & Stern, T. A. (2015). Impact of the Doctor-Patient Relationship. *Prim Care Companion CNS Disord, 17*(5). https://doi.org/10.4088/PCC.15f01840

Chong, W. W., Aslani, P., & Chen, T. F. (2013). Shared decision-making and interprofessional collaboration in mental healthcare: a qualitative study exploring perceptions of barriers and facilitators. *Journal of Interprofessional Care, 27*(5), 373-379. https://doi.org/10.3109/13561820.2013.785503

Chowdhury, S., Mok, D., & Leenen, L. (2021). Transformation of health care and the new model of care in Saudi Arabia: Kingdom's Vision 2030. *Journal of Medicine and Life, 14*(3), 347. https://doi.org/10.25122/jml-2021-0070

Chung, M. C., Juang, W. C., & Li, Y. C. (2019). Perceptions of shared decision making among health care professionals. *Journal of evaluation in clinical practice, 25*(6), 1080-1087. https://doi.org/10.1111/jep.13249

Clarke, J. (2011). What is a systematic review? *Evidence-based nursing, 14*(3), 64-64. https://doi.org/10.1136/ebn.2011.0049

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology, 12*(3), 297-298. https://doi.org/10.1080/17439760.2016.1262613

Clavel, N., Paquette, J., Dumez, V., Del Grande, C., Ghadiri, D. P., Pomey, M. P., & Normandin, L. (2021). Patient engagement in care: a scoping review of recently validated tools assessing patients' and healthcare professionals' preferences and experience. *Health Expectations, 24*(6), 1924-1935. https://doi.org/10.1111/hex.13344

Cohen, J. (1988). The Significance of a Product Moment rs. In *Statistical Power Analysis for the Behavioral Sciences* (2nd Edition ed., pp. 75-107). Routledge.

CohenMiller, A., Saban, G. A., & Bayeta, R. (2022). Rigor in Qualitative Research. *The SAGE Handbook of Qualitative Research in the Asian Context*, 327.

Connelly, L. M. (2016). Trustworthiness in Qualitative Research. *Medsurg Nursing, 25*(6), 435-436.

Conway, J., Johnson, B., Edgman-Levitan, S., Schlucter, J., Ford, D., Sodomka, P., & Simmons, L. (2006). *Partnering with patients and families to design a patient-and family-centered health care system: a roadmap for the future: a work in progress*.

Cope, D. G. (2014). Methods and meanings: credibility and trustworthiness of qualitative research. Oncology Nursing Forum,

Corbett, L. Q., & Ennis, W. J. (2014, 01 Aug). What do patients want? Patient preference in wound care [Review]. *Advances in Wound Care, 3(8)*, 537-543. https://doi.org/http://dx.doi.org/10.1089/wound.2013.0458

Couët, N., Desroches, S., Robitaille, H., Vaillancourt, H., Leblanc, A., Turcotte, S., Elwyn, G., & Légaré, F. (2015). Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expectations, 18*(4), 542-561.

Coyne, I., Holmström, I., & Söderbäck, M. (2018, 2018/09/01/). Centeredness in Healthcare: A Concept Synthesis of Family-centered Care, Person-centered Care and Child-centered Care. *Journal of pediatric nursing, 42*, 45-56. https://doi.org/10.1016/j.pedn.2018.07.001

Cramm, J. M., & Nieboer, A. P. (2016). Is "disease management" the answer to our problems? No! Population health management and (disease) prevention require "management of overall well-being". *BMC Health Services Research, 16*(1). https://doi.org/10.1186/s12913-016-1765-z

Creswell, J. W. (2008). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. SAGE Publications.

Creswell, J. W. (2011). Controversies in mixed methods research. In *The Sage handbook of qualitative research* (Vol. 4, pp. 269-284). SAGE Publication, Inc,.

Creswell, J. W. (2012). *Educational Research: Planning, Conducting, and Evaluating Quantitative and Qualitative Research*. Pearson.

Creswell, J. W., & Clark, V. L. P. (2017). *Designing and Conducting Mixed Methods Research*. SAGE Publications.

Creswell, J. W., & Creswell, J. D. (2018). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. SAGE Publications.

Creswell, J. W., Klassen, A. C., Plano Clark, V. L., & Clegg Smith, K. (2011). Best practices for mixed methods research in the health sciences. *Bethesda: National Institutes of Health, 2013*.

Creswell, J. W., Plano Clark, V., Gutmann, M. L., & Hanson, W. E. (2003). Advanced Mixed Methods Research Designs. In *The Mixed Methods Reader* (pp. 209-240).

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed. ed.). SAGE Publications.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design : choosing among five approaches* (Fourth edition. ed.). SAGE Publications, Incorporated.

Crocker, L. M., & Algina, J. (1986). *Introduction to classical and modern test theory*. Holt, Rinehart, and Winston.

Cubaka, V. K., Schriver, M., Kayitare, J. B., Cotton, P., Maindal, H. T., Nyirazinyoye, L., & Kallestrup, P. (2018). 'He should feel your pain': Patient insights on patient-provider communication in Rwanda. *Afr. J. Prim. Health Care Fam. Med., 10*(1). https://doi.org/10.4102/phcfm.v10i1.1514

Cvetanovska, N., Jessup, R. L., Wong Shee, A., Rogers, S., & Beauchamp, A. (2023). Patients' perspectives of factors influencing active participation in healthcare interactions: A qualitative study [Article]. *Patient Education and Counseling, 114*, Article 107808. https://doi.org/10.1016/j.pec.2023.107808

Datta, L. e. (1994). Paradigm wars: A basis for peaceful coexistence and beyond. *New directions for program evaluation, 1994*(61), 53-70. https://doi.org/10.1002/ev.1668

Dawn, A. G., & Lee, P. P. (2004, September/October). Patient expectations for medical and surgical care: A review of the literature and applications to ophthalmology. *Survey of Ophthalmology, 49(5)*, 513-524. https://doi.org/10.1016/j.survophthal.2004.06.004

Deen, T. L., Fortney, J. C., & Pyne, J. M. (2011). Relationship Between Satisfaction, Patient-Centered Care, Adherence and Outcomes Among Patients in A Collaborative Care Trial for Depression. *Administration and policy in mental health and mental health services research, 38*(5), 345-355. https://doi.org/10.1007/s10488-010-0322-z

Delbanco, T., Berwick, D. M., Boufford, J. I., Edgman, L., Ollenschläger, G., Plamping, D., & Rockefeller, R. G. (2001). Healthcare in a land called PeoplePower: nothing about me without me. *Health expectations : an international journal of public participation in health care and health policy, 4*(3), 144-150. https://doi.org/10.1046/j.1369-6513.2001.00145.x

Deledda, G., Moretti, F., Rimondini, M., & Zimmermann, C. (2013). How patients want their doctor to communicate. A literature review on primary care patients' perspective. *Patient Education and Counseling, 90*(3), 297-306. https://doi.org/10.1016/j.pec.2012.05.005

Demetriou, C., Özer, B., & Essau, C. (2015). Self-Report Questionnaires. In. https://doi.org/10.1002/9781118625392.wbecp507

Dent, E., Toki, D., Dupuis, N., Marquis, J., Suyeshkumar, T., & Benlamri, M. (2017). Healthcare systems within the Middle East. *University of Western Ontario Medical Journal, 86*(2), 35-36. https://doi.org/10.5206/uwomj.v86i2.2009

Devon, H. A., Block, M. E., Moyle-Wright, P., Ernst, D. M., Hayden, S. J., Lazzara, D. J., Savoy, S. M., & Kostas-Polston, E. (2007). A Psychometric Toolbox for Testing Validity and Reliability. *Journal of nursing scholarship, 39*(2), 155-164. https://doi.org/10.1111/j.1547-5069.2007.00161.x

DeWalt, D. A., Broucksou, K. A., Hawk, V., Brach, C., Hink, A., Rudd, R., & Callahan, L. (2011). Developing and testing the health literacy universal precautions toolkit. *Nursing Outlook, 59*(2), 85-94. https://doi.org/10.1016/j.outlook.2010.12.002

Dhaoui, I. (2019). Healthcare system efficiency and its determinants: A two-stage Data Envelopment Analysis (DEA) from MENA countries.

Dickerson, M. (2022). Examining the Power Dynamics in the Patient-Doctor Relationship in Bio-medicalized Countries: a Historical and Sociocultural Framework. *Independent Study Project (ISP) Collection 3532*.

Dijk, S. W., Duijzer, E. J., & Wienold, M. (2020). Role of active patient involvement in undergraduate medical education: a systematic review. *BMJ open, 10*(7), e037217. https://doi.org/10.1136/bmjopen-2020-037217

Dobscha, S. K., Cromer, R., Crain, A., & Denneson, L. M. (2016). Qualitative analysis of US Department of veterans affairs mental health clinician perspectives on patient-centered care. *International journal for quality in health care, 28*(3), 355-362. https://doi.org/10.1093/intqhc/mzw028

Dormohammadi, T., Asghari, F., & Rashidian, A. (2010). What do patients expect from their physicians? *Iranian journal of public health, 39*(1), 70-77.

Dowling, M. (2006). Approaches to reflexivity in qualitative research. *Nurse researcher, 13*(3), 7-21. https://doi.org/10.7748/nr2006.04.13.3.7.c5975

Doyle, L., Brady, A.-M., & Byrne, G. (2009). An overview of mixed methods research. *Journal of Research in Nursing, 14*(2), 175-185. https://doi.org/10.1177/1744987108093962

Drach-Zahavy, A. (2009). Patient-centred care and nurses' health: the role of nurses' caring orientation. *Journal of advanced nursing, 65*(7), 1463-1474. https://doi.org/10.1111/j.1365-2648.2009.05016.x

Dreachslin, J. L., Gilbert, M. J., & Malone, B. (2012). *Diversity and cultural competence in health care : a systems approach*. Wiley.

Du, Y., Du, Y., & Yao, N. (2020). Patient-provider relationships in China: A qualitative study on the perspectives of healthcare students and junior professionals. *PLOS ONE, 15*(10), e0240747. https://doi.org/10.1371/journal.pone.0240747

Duffy, F. D., Gordon, G. H., Whelan, G., Cole-Kelly, K., & Frankel, R. (2004). Assessing competence in communication and interpersonal skills: the Kalamazoo II report. *Academic Medicine, 79*(6), 495-507. https://doi.org/10.1097/00001888-200406000-00002

Dumez, V., & Pomey, M.-P. (2019). From medical paternalism to care partnerships: a logical evolution over several decades. In *Patient Engagement* (pp. 9-16). Springer. https://doi.org/10.1007/978-3-030-14101-1_2

Durrheim, K. (2004). Research design. In M. T. Blanche & K. Durrheim (Eds.), *Research in practice: Applied methods for the social sciences* (pp. 29-53). University of Cape Town Press

Edmonds, W. A., & Kennedy, T. D. (2017). *An Applied Guide to Research Designs: Quantitative, Qualitative, and Mixed Methods* (Second ed.) https://doi.org/10.4135/9781071802779

Edwards, M., Wood, F., Davies, M., & Edwards, A. (2012, 2012/02/14). The development of health literacy in patients with a long-term health condition: the health literacy pathway model. *BMC public health, 12*(1), 130. https://doi.org/10.1186/1471-2458-12-130

Eichner, J. M., Johnson, B. H., Betts, J. M., Chitkara, M. B., Jewell, J. A., Lye, P. S., Mirkinson, L. J., Brown, C., Heiss, K., Lostocco, L., Salerno, R. A., Percelay, J. M., Alexander, S. N., Abraham, M., Ahmann, E., Crocker, E., DiVenere, N., MacKean, G., Schwab, W. E., & Shelton, T. (2012). Patient-and family-centered care and the pediatrician's role. *PEDIATRICS, 129*(2), 394-404. https://doi.org/10.1542/peds.2011-3084

El-Haddad, C., Hegazi, I., & Hu, W. (2020). Understanding patient expectations of health care: a qualitative study. *Journal of Patient Experience, 7*(6), 1724-1731. https://doi.org/10.1177/2374373520921692

El-Khoury, G. (2009). Selected indicators of poverty in Arab countries. *Contemporary Arab Affairs, 2*(2), 355-367. https://doi.org/10.1080/17550910902853892

Elayyan, M., Rankin, J., & Chaarani, M. (2018). Factors affecting empathetic patient care behaviour among medical doctors and nurses: an integrative literature review. *East Mediterr Health J 24*(3), 311-338. https://doi.org/10.26719/2018.24.3.311

Eldh, A. C., Ehnfors, M., & Ekman, I. (2004). The Phenomena of Participation and Non-Participation in Health Care-Experiences of Patients Attending a Nurse-Led Clinic for Chronic Heart Failure. *European journal of cardiovascular nursing : journal of the Working Group on Cardiovascular Nursing of the European Society of Cardiology, 3*(3), 239-246. https://doi.org/10.1016/j.ejcnurse.2004.05.001

Eldh, A. C., Ekman, I., & Ehnfors, M. (2006). Conditions for Patient Participation and Non-Participation in Health Care. *Nursing Ethics, 13*(5), 503-514. https://doi.org/10.1191/0969733006nej898oa

Ellers, B. (1993). Involving and Supporting Family and Friends In Margaret Gerteis, Susan Edgman-Levitan, & J. Daley (Eds.), *Through the Patient's Eye: Understanding and Promoting Patient-Centered Care*. Jossey-Bass Inc.,.

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared Decision Making: A Model for Clinical Practice. *Journal of General Internal Medicine, 27*(10), 1361-1367. https://doi.org/10.1007/s11606-012-2077-6

Elwyn, G., Laitner, S., Coulter, A., Walker, E., Watson, P., & Thomson, R. (2010). Implementing shared decision making in the NHS. *BMJ, 341*(oct14 2), c5146-c5146. https://doi.org/10.1136/bmj.c5146

Elwyn, G., O'Connor, A., Stacey, D., Volk, R., Edwards, A., Coulter, A., Thomson, R., Barratt, A., Barry, M., & Bernstein, S. (2006). Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ, 333*(7565), 417. https://doi.org/10.1136/bmj.38926.629329.AE

Entwistle, V., Prior, M., Skea, Z. C., & Francis, J. J. (2008). Involvement in treatment decision-making: its meaning to people with diabetes and implications for conceptualisation. *Social science & medicine, 66*(2), 362-375. https://doi.org/10.1016/j.socscimed.2007.09.001

Entwistle, V. A., & Watt, I. S. (2013). Treating Patients as Persons: A Capabilities Approach to Support Delivery of Person-Centered Care. *American Journal of Bioethics, 13*(8), 29-39. https://doi.org/10.1080/15265161.2013.802060

Epner, D. E., & Baile, W. F. (2012, 2012/04/01/). Patient-centered care: the key to cultural competence. *Annals of Oncology, 23*, iii33-iii42. https://doi.org/10.1093/annonc/mds086

Epstein, R. M., Fiscella, K., Lesser, C. S., & Stange, K. C. (2010). Why The Nation Needs A Policy Push On Patient-Centered Health Care. *Health Affairs, 29*(8), 1489-1495. https://doi.org/10.1377/hlthaff.2009.0888

Epstein, R. M., & Street Jr, R. L. (2011). The values and value of patient-centered care. *Annals of family medicine, 9(2)*, 100-103. https://doi.org/10.1370/afm.1239

Erlen, J. A. (2004). Functional Health Illiteracy: Ethical Concerns. *Orthopaedic Nursing, 23*(2), 150-153. https://doi.org/00006416-200403000-00015

Esmaeili, M., Ali Cheraghi, M., & Salsali, M. (2014). Barriers to Patient-Centered Care: A Thematic Analysis Study. *International journal of nursing knowledge, 25*(1), 2-8. https://doi.org/10.1111/2047-3095.12012

Esmaeili, M., Cheraghi, M. A., & Salsali, M. (2014). Critical Care Nurses' Understanding of the Concept of Patient-Centered Care in Iran: A Qualitative Study. *Holistic nursing practice, 28*(1), 31-37. https://doi.org/10.1097/HNP.0000000000000002

Esmaeili, M., Cheraghi, M. A., & Salsali, M. (2016). Cardiac patients' perception of patient-centred care: a qualitative study. *Nursing in critical care, 21*(2), 97-104. https://doi.org/10.1111/nicc.12148

Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American journal of theoretical and applied statistics, 5*(1), 1-4. https://doi.org/10.11648/j.ajtas.20160501.11

Ezenkwele, U. A., & Roodsari, G. S. (2013). Cultural Competencies in Emergency Medicine: Caring for Muslim-American Patients from the Middle East. *The Journal of Emergency Medicine, 45*(2), 168-174. https://doi.org/10.1016/j.jemermed.2012.11.077

Falatah, R., Al-Harbi, L., & Alhalal, E. (2022). The Association between Cultural Competency, Structural Empowerment, and Effective Communication among Nurses in Saudi Arabia: A Cross-Sectional Correlational Study. *Nursing Reports, 12*(2), 281-290. https://doi.org/10.3390/nursrep12020028

Farooqi, J. H. (2005). Patient expectation of general practitioner care. *Midd East J Fam Med, 3*(3), 6-9.

Feeg, V. D., Paraszczuk, A. M., Çavuşoğlu, H., Shields, L., Pars, H., & Al Mamun, A. (2016). How is Family Centered Care Perceived by Healthcare Providers from Different Countries? An International Comparison Study. *Journal of pediatric nursing, 31*(3), 267-276. https://doi.org/10.1016/j.pedn.2015.11.007

Feilzer, M. Y. (2010). Doing Mixed Methods Research Pragmatically: Implications for the Rediscovery of Pragmatism as a Research Paradigm. *Journal of Mixed Methods Research, 4*(1), 6-16. https://doi.org/10.1177/1558689809349691

Feinberg, L. (2014). Moving toward person-and family-centered care. *Public Policy & Aging Report, 24*(60), 1-7. https://doi.org/10.1093/ppar/pru027

Ferguson, L. M., Ward, H., Card, S., Sheppard, S., & McMurtry, J. (2013). Putting the 'patient' back into patient-centred care: An education perspective. *Nurse Education in Practice, 13*(4), 283-287. https://doi.org/10.1016/j.nepr.2013.03.016

Ferlie, E. B., & Shortell, S. M. (2001). Improving the Quality of Health Care in the United Kingdom and the United States: A Framework for Change. *The Milbank Quarterly, 79*(2), 281-315. https://doi.org/10.1111/1468-0009.00206

Fernandes, C., Gomes, J., Martins, M. M., Gomes, B., & Gonçalves, L. (2015). The importance of families in nursing care: nurses' attitudes in the hospital environment. *Revista de enfermagem referência, 4*(7), 21-30. https://doi.org/10.12707/RIV15007

Fielding, N. G., & Fielding, J. L. (1986). *Linking data: The articulation of qualitative and quantitative methods in social research*. Beverley Hills & London

.

Figlio, K. (1977). Review of The Birth of the Clinic. An Archaeology of Medical Perception [The Birth of the Clinic. An Archaeology of Medical Perception, Michel Foucault, A. M. Sheridan-Smith]. *The British Journal for the History of Science, 10*(2), 164-167. http://www.jstor.org/stable/4025874

Filler, T., Jameel, B., & Gagliardi, A. R. (2020). Barriers and facilitators of patient centered care for immigrant and refugee women: a scoping review. *BMC public health, 20*(1), 1-1013. https://doi.org/10.1186/s12889-020-09159-6

Fisher, C. B., & Anushko, A. E. (2008). Research ethics in social science. In *The SAGE handbook of social research methods* (pp. 95-109). https://doi.org/10.4135/9781446212165

Fix, G. M., VanDeusen Lukas, C., Bolton, R. E., Hill, J. N., Mueller, N., LaVela, S. L., & Bokhour, B. G. (2018). Patient-centred care is a way of doing things: How healthcare

employees conceptualize patient-centred care. *Health Expect., 21*(1), 300-307. https://doi.org/10.1111/hex.12615

Flitcroft, K., Brennan, M., & Spillane, A. (2020). Principles of patient-centred care and barriers to their implementation: a case study of breast reconstruction in Australia. *Supportive care in cancer, 28*(4), 1963-1981. https://doi.org/10.1007/s00520-019-04978-9

Flores, G. (2000). Culture and the patient-physician relationship: Achieving cultural competency in health care. *The Journal of pediatrics, 136*(1), 14-23. https://doi.org/10.1016/s0022-3476(00)90043-x

Flynn, K. E., Smith, M. A., & Vanness, D. (2006). A typology of preferences for participation in healthcare decision making. *Social science & medicine, 63*(5), 1158-1169. https://doi.org/10.1016/j.socscimed.2006.03.030

Frampton, S. (2005). Planetree spotlight. *AJN The American Journal of Nursing, 105*(10). https://journals.lww.com/ajnonline/fulltext/2005/10000/planetree_spotlight.42.aspx

Frampton, S., Guastello, S., Brady, C., Hale, M., Horowitz, S. M., Smith, S. B., Stone, S., & Picker Institute. (2008). *Patient-centered care: improvement guide*. Planetree, Inc. and Picker Institute.

Frampton, S. B. (2001). Planetree Patient-Centered Care and the Healing Arts. *Complementary health practice review, 7*(1), 17-19. https://doi.org/10.1177/153321010100700103

Frampton, S. B. (2009). Creating a patient-centered system. *AJN The American Journal of Nursing, 109*(3), 30-33. https://doi.org/01.NAJ.0000346924.67498.ed

Frampton, S. B., Gilpin, L., & Charmel, P. A. (2003). *Putting patients first : designing and practicing patient-centered care*. Jossey-Bass.

Frankenburg, F. R. (2017). *Human Medical Experimentation: From Smallpox Vaccines to Secret Government Programs*. ABC-CLIO. https://doi.org/10.5040/9798400667275

Fredericks, M., Odiet, J. A., Miller, S. I., & Fredericks, J. (2006, Mar). Toward a conceptual reexamination of the patient-physician relationship in the healthcare institution for the new millennium. *J Natl Med Assoc, 98*(3), 378-385.

Frerichs, W., Hahlweg, P., Müller, E., Adis, C., & Scholl, I. (2016). Shared Decision-Making in Oncology – A Qualitative Analysis of Healthcare Providers' Views on Current Practice. *PLOS ONE, 11*(3), e0149789. https://doi.org/10.1371/journal.pone.0149789

Freund, P. E., McGuire, M. B., & Podhurst, L. S. (2003). *Health, illness, and the social body: A critical sociology*. Prentice Hall.

Funnell, M. M. (2004). Patient empowerment. *Critical Care Nursing Quarterly, 27*(2), 201-204. https://doi.org/00002727-200404000-00012

Gardiner, R. (2008). The transition from ‘informed patient’care to ‘patient informed’care. In *Medical and Care Compunetics 5* (Vol. 137, pp. 241-256).

Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. L. (1993). *Through the Patient's Eyes. Understanding and Promoting Patient-centered Care*.

Ghaffari, F., Ghahramanian, A., Zamanzadeh, V., Onyeka, T. C., Davoodi, A., Mazaheri, E., & Asghari-Jafarabadi, M. (2020). Patient-centred communication for women with breast cancer: Relation to body image perception. *Journal of clinical nursing, 29*(23-24), 4674-4684. https://doi.org/10.1111/jocn.15508

Ghaznawi, H. (1986). Filling the gaps in Saudi Arabia's health services. World health forum 1986; 7 (4): 353-354,

Ghiyasvandian, S., Abdolrahimi, M., Zakerimoghadam, M., & Ebadi, A. (2018). Therapeutic communication of Iranian nursing students: a qualitative study. *Pertanika Journal of Social Science and Humanities, 26*(3), 1757-1774.

Gilmer, M. J. (2002). Pediatric palliative care. *Critical Care Nursing Clinics, 14*(2), 207-214. https://doi.org/10.1016/S0899-5885(01)00013-2

Gimenes, H. T., Zanetti, M. L., & Haas, V. J. (2009). Factors related to patient adherence to antidiabetic drug therapy. *Revista Latino-Americana de Enfermagem, 17*(1), 46-51. https://doi.org/10.1590/s0104-11692009000100008

Goggins, K. M., Wallston, K. A., Nwosu, S., Schildcrout, J. S., Castel, L., Kripalani, S., & For The Vanderbilt Inpatient, C. (2014). Health Literacy, Numeracy, and Other Characteristics Associated With Hospitalized Patients' Preferences for Involvement in Decision Making. *Journal of Health Communication, 19*(sup2), 29-43. https://doi.org/10.1080/10810730.2014.938841

Goldstein, M. M., & Bowers, D. G. (2015). The Patient as Consumer: Empowerment or Commodification? Currents in Contemporary Bioethics. *Journal of Law, Medicine & Ethics, 43*(1), 162-165. https://doi.org/10.1111/jlme.12203

Gondek, D., Edbrooke-Childs, J., Velikonja, T., Chapman, L., Saunders, F., Hayes, D., & Wolpert, M. (2017). Facilitators and Barriers to Person-centred Care in Child and Young People Mental Health Services: A Systematic Review. *Clinical Psychology & Psychotherapy, 24*(4), 870-886. https://doi.org/10.1002/cpp.2052

Goodwin, N. (2014). Thinking differently about integration: people-centred care and the role of local communities. *International Journal of Integrated Care, 14*. https://doi.org/10.5334/ijic.1736

Gray, D. E. (2014). *Doing research in the real world* (3rd ed. ed.). SAGE.

Greaney, A.-M., Sheehy, A., Heffernan, C., Murphy, J., Mhaolrúnaigh, S. N., Heffernan, E., & Brown, G. (2012). Research ethics application: A guide for the novice researcher. *British Journal of Nursing, 21*(1), 38-43. https://doi.org/10.12968/bjon.2012.21.1.38

Green, H. E. (2014). Use of theoretical and conceptual frameworks in qualitative research. *Nurse researcher, 21*(6), 34-38. https://doi.org/10.7748/nr.21.6.34.e1252

Greene, J., & Hibbard, J. H. (2012). Why Does Patient Activation Matter? An Examination of the Relationships Between Patient Activation and Health-Related Outcomes. *Journal of general internal medicine : JGIM, 27*(5), 520-526. https://doi.org/10.1007/s11606-011-1931-2

Greene, J. C., & Caracelli, V. J. (1997). *Advances in mixed-method evaluation: The challenges and benefits of integrating diverse paradigms*. Jossey-Bass.

Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a Conceptual Framework for Mixed-Method Evaluation Designs. *Educational Evaluation and Policy Analysis, 11*(3), 255-274. https://doi.org/10.3102/01623737011003255

Greenfield, S., Kaplan, S., & Ware Jr, J. E. (1985). Expanding patient involvement in care: effects on patient outcomes. *Annals of Internal Medicine, 102*(4), 520-528. https://doi.org/10.7326/0003-4819-102-4-520

Gremigni, P., Casu, G., & Sommaruga, M. (2016). Dealing with patients in healthcare: A self-assessment tool. *Patient Education and Counseling, 99*(6), 1046-1053. https://doi.org/10.1016/j.pec.2016.01.015

Griffin, S. J., Kinmonth, A.-L., Veltman, M. W. M., Gillard, S., Grant, J., & Stewart, M. (2004). Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. *Annals of family medicine, 2*(6), 595-608. https://doi.org/10.1370/afm.142

Grilo, A. M., Dos Santos, M. C., Gomes, A. I., & Rita, J. S. (2017). Promoting Patient-Centered Care in Chronic Disease. In. InTech. https://doi.org/10.5772/67380

Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *ECTJ, 29*(2). https://doi.org/10.1007/bf02766777

Guess, C. D. (2004). Decision making in individualistic and collectivistic cultures. *Online readings in psychology and culture, 4*(1), 3. https://doi.org/10.9707/2307-0919.1032

Gunasekare, D. U. (2015). Mixed research method as the third research paradigm: a literature review. *International Journal of Science and Research (IJSR), 4*(8), 361-367.

Ha, J. F., Anat, D. S., & Longnecker, N. (2010). Doctor-patient communication: a review. *Ochsner Journal, 10*(1), 38-43.

Haidet, P., Kelly, P. A., Chou, C., The Communication, C., & Culture Study, G. (2005). Characterizing the Patient-Centeredness of Hidden Curricula in Medical Schools: Development and Validation of a New Measure. *Academic Medicine, 80*(1). https://journals.lww.com/academicmedicine/fulltext/2005/01000/characterizing_the_patient_centeredness_of_hidden.12.aspx

Håkansson Eklund, J., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., Sundler, A. J., Condén, E., & Summer Meranius, M. (2019). "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Education and Counseling, 102*(1), 3-11. https://doi.org/10.1016/j.pec.2018.08.029

Halcomb, E. J., & Hickman, L. (2015). Mixed methods research. *Faculty of Science, Medicine and Health - Papers: part A*. https://doi.org/10.7748/ns.29.32.41.e8858

Hall, M. A., Dugan, E., Zheng, B., & Mishra, A. K. (2001). Trust in Physicians and Medical Institutions: What Is It, Can It Be Measured, and Does It Matter? *The Milbank Quarterly, 79*(4), 613-639. https://doi.org/10.1111/1468-0009.00223

Halligan, P. (2006). Caring for patients of Islamic denomination: critical care nurses' experiences in Saudi Arabia. *Journal of clinical nursing, 15*(12), 1565-1573. https://doi.org/10.1111/j.1365-2702.2005.01525.x

Han, C. J. (2016). A Concept Analysis of Personalized Health Care in Nursing. *Nursing Forum, 51*(1), 32-39. https://doi.org/10.1111/nuf.12117

Hanson, C. S., Ju, A., & Tong, A. (2019). Appraisal of Qualitative Studies. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (1st ed. 2019. ed., pp. 1013-1026). Springer Nature Singapore. https://doi.org/10.1007/978-981-10-5251-4

Hany, A., & Vatmasari, R. A. (2021). Correlation between nurse-patient interaction and readiness to care for post-treated heart failure patients in the intensive care room Malang, Indonesia. *Journal of Public Health Research, 10*(2), jphr. 2021.2229. https://doi.org/10.4081/jphr.2021.2229

Haq, Z. U., Rasheed, R., Rashid, A., & Akhter, S. (2023). Criteria for Assessing and Ensuring the Trustworthiness in Qualitative Research. *International Journal of Business Reflections, 4*(2). https://doi.org/10.56249/ijbr.03.01.44

Harding, E., Wait, S., & Scrutton, J. (2015). *The state of play in person-centred care*.

Hasnain, M., Connell, K. J., Menon, U., & Tranmer, P. A. (2011). Patient-Centered Care for Muslim Women: Provider and Patient Perspectives. *Journal of Women's Health, 20*(1), 73-83. https://doi.org/10.1089/jwh.2010.2197

Hassan, A., Mahmood, K., & Bukhsh, H. A. (2017). Healthcare system of Pakistan. *IJARP, 1*(4), 170-173.

Hawthorne, G., Hrisos, S., Stamp, E., Elovainio, M., Francis, J. J., Grimshaw, J. M., Hunter, M., Johnston, M., Presseau, J., Steen, N., & Eccles, M. P. (2012). Diabetes care provision in UK primary care practices [Research Support, Non-U.S. Gov't]. *PLoS ONE [Electronic Resource], 7*(7), e41562. https://doi.org/10.1371/journal.pone.0041562

Hayajneh, F. A., & Shehadeh, A. (2014). The impact of adopting person-centred care approach for people with Alzheimer's on professional caregivers' burden: An interventional study. *International journal of nursing practice, 20*(4), 438-445. https://doi.org/10.1111/ijn.12251

Hayes, B., Bonner, A., & Douglas, C. (2013). An introduction to mixed methods research for nephrology nurses. *Renal Society of Australasia Journal, 9*(1), 8-14.

Health Foundation. (2016). Person-centred care made simple: what everyone should know about person-centred care. https://www.health.org.uk/sites/default/files/PersonCentredCareMadeSimple.pdf

Health Sector Transformation Program. (2021). *Health Sector Transformation Program delivery Plan* Retrieved 21 Jan 2023 from https://www.vision2030.gov.sa/media/0wop2tds/hstp_eng.pdf

Henson, R. K. (2001). Understanding Internal Consistency Reliability Estimates: A Conceptual Primer on Coefficient Alpha. *Measurement and Evaluation in Counseling and Development, 34*(3), 177-189. https://doi.org/10.1080/07481756.2002.12069034

Hesse-Biber, S. N. (2010). *Mixed methods research: Merging theory with practice*. Guilford Press.

Hijazi, H. H., Harvey, H. L., Alyahya, M. S., Alshraideh, H. A., Al abdi, R. M., & Parahoo, S. K. (2018). The Impact of Applying Quality Management Practices on Patient Centeredness in Jordanian Public Hospitals: Results of Predictive Modeling. *Inquiry (Chicago), 55*, 46958018754739-46958018754739. https://doi.org/10.1177/0046958018754739

Hoffmann, T. C., Légaré, F., Simmons, M. B., McNamara, K., McCaffery, K., Trevena, L. J., Hudson, B., Glasziou, P. P., & Del Mar, C. B. (2014). Shared decision making: what do clinicians need to know and why should they bother? *Medical Journal of Australia, 201*(1), 35-39. https://doi.org/10.5694/mja14.00002

Hoffmann, T. C., Lewis, J., & Maher, C. G. (2020, 2020/06/01/). Shared decision making should be an integral part of physiotherapy practice. *Physiotherapy, 107*, 43-49. https://doi.org/https://doi.org/10.1016/j.physio.2019.08.012

Hofstede, G., Hofstede, G. J., & Minkov, M. (2010). *Cultures and organizations : software of the mind : intercultural cooperation and its importance for survival* (Revised and expanded 3rd edition. ed.). McGraw-Hill.

Hofstede, S. N., Marang-Van De Mheen, P. J., Wentink, M. M., Stiggelbout, A. M., Vleggeert-Lankamp, C. L., Vliet Vlieland, T. P., & Van Bodegom-Vos, L. (2013). Barriers and facilitators to implement shared decision making in multidisciplinary sciatica care: a qualitative study. *Implementation Science, 8*(1), 95. https://doi.org/10.1186/1748-5908-8-95

Horvath, A. O. (2000). The therapeutic relationship: From transference to alliance. *Journal of clinical psychology, 56*(2), 163-173. https://doi.org/10.1002/(SICI)1097-4679(200002)56:2%3C163::AID-JCLP3%3E3.0.CO;2-D

Howie, J. G. R., Heaney, D., & Maxwell, M. (2004). Quality, core values and the general practice consultation: issues of definition, measurement and delivery. *Family practice, 21*(4), 458-468. https://doi.org/10.1093/fampra/cmh419

Hoy, E. (2008). Measuring patient experiences of care. *Bulletin of the American College of Surgeons, 93*(5), 13-16.

Hughes, J. C., Bamford, C., & May, C. (2008). Types of centredness in health care: themes and concepts. *Medicine, Health Care and Philosophy, 11*(4), 455-463. https://doi.org/10.1007/s11019-008-9131-5

Hurst, D. J., Potter, J., Naumann, P., Baig, J. A., Evatt, M., Lockhart, J. S., & Gielen, J. (2022). Barriers to Patient Involvement in Decision-Making in Advanced Cancer Care: Culture as an Amplifier [Article]. *Narrative Inquiry in Bioethics, 12*(1), 77-92. https://doi.org/10.1353/nib.2022.0018

Hwang, S. M., Lee, J. J., Jang, J. S., Gim, G. H., Kim, M. C., & Lim, S. Y. (2014). Patient preference and satisfaction with their involvement in the selection of an anesthetic method for surgery. *Journal of Korean medical science, 29*(2), 287-291. https://doi.org/10.3346/jkms.2014.29.2.287

Ibrahim, A., Albaqawy, G., & Said, M. (2021, 03/05). Tourism attraction sites: Boosting the booming tourism of Saudi Arabia. *International Journal of Advanced and Applied Sciences, 8(4) 2021*, 1-11. https://doi.org/10.21833/ijaas.2021.04.001

IDF Diabetes Atlas. (2021). *IDF Diabetes Atlas - Saudi Arabia Diabetes Report 2000-2045* . Retrieved 26 June 2023 from https://diabetesatlas.org/data/en/country/174/sa.html

Igel, L. H., & Lerner, B. H. (2016). Moving past individual and "pure" autonomy: the rise of family-centered patient care. *AMA Journal of Ethics, 18*(1), 56-62.

Institute For Patient and Family Centered Care. (2024). *Université de Montréal*. Retrieved 6 June 2024 from https://www.ipfcc.org/bestpractices/ipe/ipe-programs-students-montreal.html

Institute for Patient- and Family-Centered Care. (2017). ADVANCING THE PRACTICE OF PATIENT- AND FAMILY-CENTERED CARE IN HOSPITALS How to Get Started. https://www.ipfcc.org/resources/getting_started.pdf

Institute of Medicine. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academies Press.

Institute of Patient and Family Centered Care. (2021). *Patient and Family centered care* Retrieved 26 August 2021 from https://www.ipfcc.org/about/pfcc.html

International Alliance of Patients' Organizations. (2007). *What is patient-centred health care? A review of definitions and principles*.

International Diabetes Federation. (2021). *IDF Diabetes Atlas 10th edition* IDF. Retrieved 16 November 2022 from https://diabetesatlas.org/idfawp/resource-files/2021/07/IDF_Atlas_10th_Edition_2021.pdf

International Trade Administration. (2022). *SAUDI ARABIA LAUNCHES HEALTH CLUSTERS*. Retrieved 15 Jun 2023 from https://www.trade.gov/market-intelligence/saudi-arabia-launches-health-clusters

Inzucchi, S. E., Bergenstal, R. M., Buse, J. B., Diamant, M., Ferrannini, E., Nauck, M., Peters, A. L., Tsapas, A., Wender, R., & Matthews, D. R. (2012). Management of hyperglycaemia in type 2 diabetes: a patient-centered approach. Position statement of the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD). *Diabetologia, 55*(6), 1577-1596. https://doi.org/10.1007/s00125-012-2534-0

Ishikawa, H., & Yamazaki, Y. (2005). How Applicable are Western Models of Patient-Physician Relationship in Asia?: Changing Patient-Physician Relationship in Contemporary Japan. *International Journal of Japanese Sociology, 14*(1), 84-93. https://doi.org/10.1111/j.1475-6781.2005.00070.x

Ivynian, S. E., Newton, P. J., & Digiacomo, M. (2020). Patient preferences for heart failure education and perceptions of patient–provider communication. *Scandinavian journal of caring sciences, 34*(4), 1094-1101. https://doi.org/10.1111/scs.12820

Jannadi, B., Alshammari, H., Khan, A., & Hussain, R. (2008). Current structure and future challenges for the healthcare system in Saudi Arabia. *Asia Pacific Journal of Health Management, 3*(1), 43-50.

Jasemi, M., Valizadeh, L., Zamanzadeh, V., & Keogh, B. (2017, Jan-Mar). A Concept Analysis of Holistic Care by Hybrid Model. *Indian J Palliat Care, 23*(1), 71-80. https://doi.org/10.4103/0973-1075.197960

Jayadevappa, R., & Chhatre, S. (2011). Patient centered care-a conceptual model and review of the state of the art. *The Open Health Services and Policy Journal, 4*(1). https://doi.org/10.2174/1874924001104010015

Jenerette, C. M., & Mayer, D. K. (2016, 2016/05/01/). Patient-Provider Communication: the Rise of Patient Engagement. *Seminars in Oncology Nursing, 32*(2), 134-143. https://doi.org/10.1016/j.soncn.2016.02.007

Jenkinson, C. (2002). The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. *International journal for quality in health care, 14*(5), 353-358. https://doi.org/10.1093/intqhc/14.5.353

Jenkinson, C., Coulter, A., Reeves, R., Bruster, S., & Richards, N. (2003). Properties of the Picker Patient Experience questionnaire in a randomized controlled trial of long

versus short form survey instruments. *Journal of Public Health, 25*(3), 197-201. https://doi.org/10.1093/pubmed/fdg049

Jiang, N., Sun, M. M., Zhou, Y. Y., & Feng, X. X. (2021). Significance of Patient Participation in Nursing Care. *Alternative Therapies in Health and Medicine, 27*(5), 115-119.

Jo Delaney, L. (2018a). Patient-centred care as an approach to improving health care in Australia. *Collegian (Royal College of Nursing, Australia), 25*(1), 119-123. https://doi.org/10.1016/j.colegn.2017.02.005

Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed Methods Research: A Research Paradigm Whose Time Has Come. *Educational Researcher, 33*(7), 14-26. https://doi.org/10.3102/0013189x033007014

Joolaee, S., Joolaei, A., Tschudin, V., Bahrani, N., & Nikbakht, A. N. (2010). Caring relationship: the core component of patients' rights practice as experienced by patients and their companions. *Journal of medical ethics and history of medicine, 3*, 1.

Kabasakal, H., Dastmalchian, A., Karacay, G., & Bayraktar, S. (2012). Leadership and culture in the MENA region: An analysis of the GLOBE project. *Journal of World Business, 47*(4), 519-529. https://doi.org/10.1016/j.jwb.2012.01.005

Kagawa-Singer, M., Valdez Dadia, A., Yu, M. C., & Surbone, A. (2010). Cancer, Culture, and Health Disparities: Time to Chart a New Course? *CA: A Cancer Journal for Clinicians, 60*(1), 12-39. https://doi.org/10.3322/caac.20051

Kalateh Sadati, A., Bagheri Lankarani, K., & Hemmati, S. (2016). Patients' description of unexpected interactions: a critical ethnography of the quality of doctor-patient interactions in one educational hospital in Shiraz, Iran. *Shiraz E-Medical Journal, 17*(7-8).

Kamimura, A., Higham, R., Rathi, N., Panahi, S., Lee, E., & Ashby, J. (2020). Patient–provider relationships among vulnerable patients: the association with health literacy, continuity of care, and self-rated health. *Journal of Patient Experience, 7*(6), 1450-1457. https://doi.org/10.1177/2374373519895680

Karazivan, P., Dumez, V., Flora, L., Pomey, M.-P., Del Grande, C., Ghadiri, D. P., Fernandez, N., Jouet, E., Las Vergnas, O., & Lebel, P. (2015). The Patient-as-Partner Approach in Health Care: A Conceptual Framework for a Necessary Transition. *Academic Medicine, 90*(4). https://doi.org/10.1097/ACM.0000000000000603

Kasim, T. S. A. T. (2014). Teaching paradigms: An analysis of traditional and student-centred approaches. *Jurnal Usuluddin, 40*, 199-218.

Kazdin, A. E. (2003). *Research design in clinical psychology* (4th ed. ed.). Allyn and Bacon.

Kerasidou, A., Bærøe, K., Berger, Z., & Caruso Brown, A. E. (2021). The need for empathetic healthcare systems. *Journal of Medical Ethics, 47*(12), e27-e27. https://doi.org/10.1136/medethics-2019-105921

Khaliq, A. A. (2012). The Saudi health care system: a view from the minaret. *World health & population, 13*(3), 52-64.

Khamis, H. (2008). Measures of association: how to choose? *Journal of Diagnostic Medical Sonography, 24*(3), 155-162. https://doi.org/10.1177/8756479308317006

Kherallah, M., Alahfez, T., Sahloul, Z., Eddin, K. D., & Jamil, G. (2012). Health care in Syria before and during the crisis. *Avicenna journal of medicine, 2*(3), 51. https://doi.org/10.4103/2231-0770.102275

Khullar, N., & Coughlan, R. (2018). Person-centered versus disease-centered narratives among mental health providers in Kuwait: A critical and qualitative analysis of iatrogenesis and .global medical discourse in action. *International journal of mental health, 47*(4), 254-283. https://doi.org/10.1080/00207411.2018.1504565

Kiger, M. E., & Varpio, L. (2020). Thematic analysis of qualitative data: AMEE Guide No. 131. *Medical Teacher, 42*(8), 846-854. https://doi.org/10.1080/0142159x.2020.1755030

Kim, S., & Kim, M. (2023). Nursing students' experiences and perceptions of barriers to the implementation of person-centred care in clinical settings: A qualitative study. *Nursing Open, 10*(3), 1889-1899. https://doi.org/10.1002/nop2.1514

Kim, S. C., Kim, S., & Boren, D. (2008). The Quality of Therapeutic Alliance between Patient and Provider Predicts General Satisfaction. *Military Medicine, 173*(1), 85-90. https://doi.org/10.7205/milmed.173.1.85

Kimberlin, C. L., & Winterstein, A. G. (2008). Validity and reliability of measurement instruments used in research. *American Journal of Health-System Pharmacy, 65*(23), 2276-2284. https://doi.org/10.2146/ajhp070364

King, A., & Hoppe, R. B. (2013). “Best Practice” for Patient-Centered Communication: A Narrative Review. *Journal of Graduate Medical Education, 5*(3), 385-393. https://doi.org/10.4300/jgme-d-13-00072.1

Kivunja, C., & Kuyini, A. B. (2017). Understanding and applying research paradigms in educational contexts. *International Journal of higher education, 6*(5), 26-41. https://doi.org/10.5430/ijhe.v6n5p26

Koeck, C. (2014). Imbalance of power between patients and doctors. *BMJ : British Medical Journal, 349*, g7485. https://doi.org/10.1136/bmj.g7485

Kokorelias, K. M., Gignac, M. A. M., Naglie, G., & Cameron, J. I. (2019). Towards a universal model of family centered care: a scoping review. *BMC Health Services Research, 19*(1). https://doi.org/10.1186/s12913-019-4394-5

Komrad, M. S. (1983). A defence of medical paternalism: maximising patients' autonomy. *Journal of Medical Ethics, 9*(1), 38-44. https://doi.org/10.1136/jme.9.1.38

Kovacs Burns, K., Bellows, M., Eigenseher, C., & Gallivan, J. (2014). 'Practical' resources to support patient and family engagement in healthcare decisions: a scoping review. *BMC Health Services Research, 14*(1), 175-175. https://doi.org/10.1186/1472-6963-14-175

Kravitz, R. L. (1996). Patients' Expectations for Medical Care: An Expanded Formulation Based on Review of the Literature. *Medical care research and review, 53*(1), 3-27. https://doi.org/10.1177/107755879605300101

Kronfol, N. M. (2012). Access and barriers to health care delivery in Arab countries: a review. *Eastern Mediterranean health journal, 18*(12), 1239-1246. https://doi.org/10.26719/2012.18.12.1239

Kuipers, S. J., Cramm, J., & Nieboer, A. (2019). The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-morbidity in the primary care setting. *BMC Health Services Research, 19*(1), 1-9. https://doi.org/10.1186/s12913-018-3818-y

Kuipers, S. J., Nieboer, A. P., & Cramm, J. M. (2021). Easier said than done: Healthcare professionals' barriers to the provision of patient-centered primary care to patients with multimorbidity. *International journal of environmental research and public health, 18*(11), 6057. https://doi.org/10.3390/ijerph18116057

Kurji, Z., Premani, Z. S., & Mithani, Y. (2016). Analysis of the health care system of Pakistan: lessons learnt and way forward. *J Ayub Med Coll Abbottabad, 28*(3), 601.

Kurtz, S. M. (2002). Doctor-Patient Communication: Principles and Practices. *Canadian Journal of Neurological Sciences / Journal Canadien des Sciences Neurologiques, 29*(S2), S23-S29. https://doi.org/10.1017/s0317167100001906

Kwak, S. G., & Kim, J. H. (2017). Central limit theorem: the cornerstone of modern statistics. *Korean Journal of Anesthesiology, 70*(2), 144. https://doi.org/10.4097/kjae.2017.70.2.144

Kwame, A., & Petrucka, P. M. (2021). A literature-based study of patient-centered care and communication in nurse-patient interactions: barriers, facilitators, and the way forward [Review]. *BMC Nursing, 20*(1), Article 158. https://doi.org/10.1186/s12912-021-00684-2

Lamadah, S. M., & Sayed, H. Y. (2014). Challenges facing nursing profession in Saudi Arabia. *Journal of Biology, Agriculture and Healthcare, 4*(7), 20-25.

Lateef, F. (2011). Patient expectations and the paradigm shift of care in emergency medicine. *Journal of emergencies, trauma and shock, 4*(2), 163. https://doi.org/10.4103/0974-2700.82199

Lazcano-Ponce, E., Angeles-Llerenas, A., Rodríguez-Valentín, R., Salvador-Carulla, L., Domínguez-Esponda, R., Astudillo-García, C. I., Madrigal-de León, E., & Katz, G. (2020). Communication patterns in the doctor–patient relationship: evaluating determinants associated with low paternalism in Mexico. *BMC Medical Ethics, 21*, 1-11. https://doi.org/10.1186/s12910-020-00566-3

Leavy, P. (2017). *Research Design: Quantitative, Qualitative, Mixed Methods, Arts-Based, and Community-Based Participatory Research Approaches*. Guilford Publications.

Lee, S. F., Kristjanson, L. J., & Williams, A. M. (2009). Professional relationships in palliative care decision making [Article]. *Supportive care in cancer, 17*(4), 445-450. https://doi.org/10.1007/s00520-008-0516-z

Lee, Y. K., & Ng, C. J. (2017, 2017/06/01/). The state of shared decision making in Malaysia. *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 123-124*, 66-68. https://doi.org/10.1016/j.zefq.2017.05.019

Leonardsen, A.-C. L., Grøndahl, V. A., Ghanima, W., Storeheier, E., Schönbeck, A., Løken, T.-A., Bakken, N. C. M., Letting, G. S., Holst, R., & Jelsness-Jørgensen, L.-P. (2017, 2017/09/29). Evaluating patient experiences in decentralised acute care using the Picker Patient Experience Questionnaire; methodological and clinical findings. *BMC Health Services Research, 17*(1), 685. https://doi.org/10.1186/s12913-017-2614-4

Levinson, W., Kao, A., Kuby, A., & Thisted, R. A. (2005). Not all patients want to participate in decision making : A national study of public preferences. *Journal of general internal medicine : JGIM, 20*(6), 531-535. https://doi.org/10.1111/j.1525-1497.2005.04101.x

Li, C., & Khan, M. M. (2022, 2022/08/30). Public trust in physicians: empirical analysis of patient-related factors affecting trust in physicians in China. *BMC Primary Care, 23*(1), 217. https://doi.org/10.1186/s12875-022-01832-6

Liang, Z., Xu, M., Liu, G., Zhou, Y., & Howard, P. (2022, 2022/04/08). Patient-centred care and patient autonomy: doctors' views in Chinese hospitals. *BMC Medical Ethics, 23*(1), 38. https://doi.org/10.1186/s12910-022-00777-w

Lin, C.-J., Lee, C.-K., & Huang, M.-C. (2017). Cultural competence of healthcare providers: A systematic review of assessment instruments. *Journal of Nursing Research, 25*(3), 174-186. https://doi.org/10.1097/JNR.0000000000000153

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications.

Lipovetski, O., & Cojocaru, D. (2020). Achieving Patient-Centered Care with Shared Decision-Making among Colorectal Cancer Patients in Israel. *Revista de cercetare şi intervenţie socială, 70*, 250-264. https://doi.org/10.33788/rcis.70.15

Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., Ferrier, K., & Payne, S. (2001). Preferences of patients for patient centred approach to consultation in primary care: observational study. *BMJ, 322*(7284), 468. https://doi.org/10.1136/bmj.322.7284.468

Loghmani, L., Borhani, F., & Abbaszadeh, A. (2014, Mar). Factors affecting the nurse-patients' family communication in intensive care unit of kerman: a qualitative study. *J Caring Sci, 3*(1), 67-82. https://doi.org/10.5681/jcs.2014.008

Loh, A., Simon, D., Wills, C. E., Kriston, L., Niebling, W., & Härter, M. (2007). The effects of a shared decision-making intervention in primary care of depression: A cluster-randomized controlled trial. *Patient Education and Counseling, 67*(3), 324-332. https://doi.org/10.1016/j.pec.2007.03.023

Lumley, T., Diehr, P., Emerson, S., & Chen, L. (2002). The Importance of the Normality Assumption in Large Public Health Data Sets. *Annual Review of Public Health, 23*(1), 151-169. https://doi.org/10.1146/annurev.publhealth.23.100901.140546

Luxford, K., Piper, D., Dunbar, N., & Poole, N. (2010). *Patient-centred care: improving quality and safety by focusing care on patients and consumers*. Australian Commission on Safety and Quality in Health Care (ACSQHC).

Mahboub, B., Mawasi, A., Ali, S., & Spina, C. (2018). Patients' satisfaction as a dimension of quality: a survey on outpatients' care in Dubai. *International journal of health care quality assurance, 31*(8), 1030-1043. https://doi.org/10.1108/IJHCQA-10-2017-0188

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative health research, 26*(13), 1753-1760. https://doi.org/10.1177/1049732315617444

Manchaiah, V., Gomersall, P. A., Tomé, D., Ahmadi, T., & Krishna, R. (2014). Audiologists' preferences for patient-centredness: a cross-sectional questionnaire study of cross-cultural differences and similarities among professionals in Portugal, India and Iran. *BMJ open, 4*(10), e005915-e005915. https://doi.org/10.1136/bmjopen-2014-005915

Mansell, D., Poses, R. M., Kazis, L., & Duefield, C. A. (2000). Clinical Factors That Influence Patients' Desire for Participation in Decisions About Illness. *Archives of internal medicine (1960), 160*(19), 2991-2996. https://doi.org/10.1001/archinte.160.19.2991

Marczyk, G. R., DeMatteo, D., & Festinger, D. (2005). *Essentials of research design and methodology*. John Wiley & Sons.

Marshall, C., & Rossman, G. B. (2011). *Designing qualitative research* (5th ed. ed.). SAGE.

Mate, K., Deen, N., McCall, J., & Bryan, C. (2016). Review of Health Systems of the Middle East and North Africa Region. 347-356. https://doi.org/10.1016/B978-0-12-803678-5.00303-9

Matin, M., & Lebaron, S. (2004). Attitudes Toward Cervical Cancer Screening Among Muslim Women: A Pilot Study. *Women & Health, 39*(3), 63-77. https://doi.org/10.1300/j013v39n03_05

Matthias, M. S., Parpart, A. L., Nyland, K. A., Huffman, M. A., Stubbs, D. L., Sargent, C., & Bair, M. J. (2010). The Patient-Provider Relationship in Chronic Pain Care: Providers' Perspectives. *Pain medicine (Malden, Mass.), 11*(11), 1688-1697. https://doi.org/10.1111/j.1526-4637.2010.00980.x

Matusitz, J., & Spear, J. (2015). Doctor-Patient Communication Styles: A Comparison Between the United States and Three Asian Countries. *Journal of Human Behavior in the Social Environment, 25*(8), 871-884. https://doi.org/10.1080/10911359.2015.1035148

Maurtvedt, F. (2006). *Between heaven and hell, and education is the salvation?: how adolecent girls understand the importance of secondary education and what they expect from it. A case from Uganda.* [Master of Philosophy, University of Oslo]. Oslo.

Maxwell, J. (1992). Understanding and Validity in Qualitative Research. *Harvard Educational Review, 62*(3), 279-301. https://doi.org/10.17763/haer.62.3.8323320856251826

Maxwell, J. A. (2012). *Qualitative research design: An interactive approach*. Sage publications.

McBride, E., Hacking, B., O'Carroll, R., Young, M., Jahr, J., Borthwick, C., Callander, A., & Berrada, Z. (2016). Increasing patient involvement in the diabetic foot pathway: a pilot randomized controlled trial. *Diabetic medicine, 33*(11), 1483-1492. https://doi.org/10.1111/dme.13158

McCormack, B., & McCance, T. (2016). Underpinning principles of person-centred practice. In *Person-Centred Practice in Nursing and Health Care: Theory and Practice*. Wiley.

McLean, M., Al Yahyaei, F., Al Mansoori, M., Al Ameri, M., Al Ahbabi, S., & Bernsen, R. (2012). Muslim Women's Physician Preference: Beyond Obstetrics and Gynecology. *Health Care for Women International, 33*(9), 849-876. https://doi.org/10.1080/07399332.2011.645963

McMillan, S. S., Kendall, E., Sav, A., King, M. A., Whitty, J. A., Kelly, F., & Wheeler, A. J. (2013, December). Patient-centered approaches to health care: A systematic review of randomized controlled trials [Review]. *Medical care research and review, 70(6)*, 567-596. https://doi.org/10.1177/1077558713496318

McNair, R., Griffiths, L., Reid, K., & Sloan, H. (2016, 2016/07/15). Medical students developing confidence and patient centredness in diverse clinical settings: a longitudinal survey study. *BMC Medical Education, 16*(1), 176. https://doi.org/10.1186/s12909-016-0689-y

Mead, E. L., Doorenbos, A. Z., Javid, S. H., Haozous, E. A., Arviso Alvord, L., Flum, D. R., & Morris, A. M. (2013). Shared Decision-Making for Cancer Care Among Racial and Ethnic Minorities: A Systematic Review. *American Journal of Public Health, 103*(12), e15-e29. https://doi.org/10.2105/AJPH.2013.301631

Mead, N., & Bower, P. (2000a). Patient-centredness: a conceptual framework and review of the empirical literature. *Social science & medicine, 51*(7), 1087-1110. https://doi.org/10.1016/s0277-9536(00)00098-8

Medina-Artom, T. R., & Adashi, E. Y. (2020). Patient-centered care in Israeli IVF units: divergent perceptions of patients and providers. *Israel journal of health policy research, 9*(1), 1-39. https://doi.org/10.1186/s13584-020-00395-0

Mertens, D. M. (2007). Transformative paradigm: Mixed methods and social justice. *Journal of Mixed Methods Research, 1*(3), 212-225. https://doi.org/10.1177/1558689807302811

Migiro, S., & Magangi, B. (2011). Mixed methods: A review of literature and the future of the new research paradigm. *African journal of business management, 5*(10), 3757-3764. https://doi.org/10.5897/AJBM09.082

Millenson, M. L., Shapiro, E., Greenhouse, P. K., & DiGioia III, A. M. (2016). Patient-and family-centered care: a systematic approach to better ethics and care. *AMA Journal of Ethics, 18*(1), 49-55. https://doi.org/10.1001/journalofethics.2017.18.1.stas1-1601

Miller, K. L. (2016). Patient centered care: a path to better health outcomes through engagement and activation. *NeuroRehabilitation, 39*(4), 465-470. https://doi.org/10.3233/NRE-161378

Ministry of Health. (2013a). *Health Statistics Annual Book*. Retrieved 23 Oct 2023 from https://www.moh.gov.sa/en/Ministry/Statistics/book/Documents/Statistics-Book-1434.pdf

Ministry of Health. (2013b). *Survey of Health Information in th Kingdom of Saudi Arabia* https://www.moh.gov.sa/Ministry/Statistics/Documents/Final%20book.pdf

Ministry of Health. (2014). *Health Statistics Annual Book*. Retrieved 23 Oct 2023 from https://www.moh.gov.sa/en/Ministry/Statistics/book/Documents/Statistical-Book-for-the-Year-1435.pdf

Ministry of Health. (2018). *Statistical Yearbook 2018*. Retrieved 17 March 2023 from https://www.moh.gov.sa/en/Ministry/Statistics/book/Documents/book-Statistics.pdf

Ministry of Health. (2019). *World Health Survey Saudi Arabia (KSAWAS) 2019 Final Report*. https://www.moh.gov.sa/en/Ministry/Statistics/Population-Health-Indicators/Documents/World-Health-Survey-Saudi-Arabia.pdf

Ministry of Health. (2021). *Statistical Yearbook 2021*. MoH. Retrieved May 5, 2023 from https://www.moh.gov.sa/en/Ministry/Statistics/book/Documents/Statistical-Yearbook-2021.pdf

Ministry of Health's Vision Realization Office. (2019). *Healthcare Transformation Strategy*. Retrieved 12 May 2021 from https://www.moh.gov.sa/en/Ministry/vro/Documents/Healthcare-Transformation-Strategy.pdf

Mishra, P., Pandey, C. M., Singh, U., Gupta, A., Sahu, C., & Keshri, A. (2019). Descriptive statistics and normality tests for statistical data. *Annals of cardiac anaesthesia, 22*(1), 67. https://doi.org/10.4103/aca.ACA_157_18

Mitton, C., Smith, N., Peacock, S., Evoy, B., & Abelson, J. (2009). Public participation in health care priority setting: a scoping review. *Health Policy, 91*(3), 219-228. https://doi.org/10.1016/j.healthpol.2009.01.005

Moazam, F. (2000). Families, Patients, and Physicians in Medical Decisionmaking: A Pakistani Perspective. *The Hastings Center Report, 30*(6), 28. https://doi.org/10.2307/3528451

Mobeireek, A. F., Al-Kassimi, F., Al-Zahrani, K., Al-Shimemeri, A., Al-Damegh, S., Al-Amoudi, O., Al-Eithan, S., Al-Ghamdi, B., & Gamal-Eldin, M. (2008). Information disclosure and decision-making: The Middle East versus the Far East and the West [Article]. *Journal of Medical Ethics, 34*(4), 225-229. https://doi.org/10.1136/jme.2006.019638

Mohamed, H., Al-Lenjawi, B., Amuna, P., Zotor, F., & Elmahdi, H. (2013). Culturally sensitive patient-centred educational programme for self-management of type 2 diabetes: A randomized controlled trial. *Primary care diabetes, 7*(3), 199-206. https://doi.org/10.1016/j.pcd.2013.05.002

Mole, T. B., Begum, H., Cooper-Moss, N., Wheelhouse, R., MacKeith, P., Sanders, T., & Wass, V. (2016). Limits of 'patient-centredness': valuing contextually specific communication patterns. *Medical education, 50*(3), 359-369. https://doi.org/10.1111/medu.12946

Montori, V. M., Gafni, A., & Charles, C. (2006). A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expectations, 9*(1), 25-36. https://doi.org/10.1111/j.1369-7625.2006.00359.x

Moore, L., Britten, N., Lydahl, D., Naldemirci, Ö., Elam, M., & Wolf, A. (2017). Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scandinavian journal of caring sciences, 31*(4), 662-673. https://doi.org/10.1111/scs.12376

Morley, L., & Cashell, A. (2017, 2017/06/01/). Collaboration in Health Care. *Journal of Medical Imaging and Radiation Sciences, 48*(2), 207-216. https://doi.org/https://doi.org/10.1016/j.jmir.2017.02.071

Moudatsou, M., Stavropoulou, A., Philalithis, A., & Koukouli, S. (2020). The Role of Empathy in Health and Social Care Professionals. *Healthcare, 8*(1), 26. https://doi.org/10.3390/healthcare8010026

Mowafi, H. (2011). Conflict, displacement and health in the Middle East. *Global public health, 6*(5), 472-487. https://doi.org/10.1080/17441692.2011.570358

Mufti, M. H. (2000). *Healthcare Development Strategies in the Kingdom of Saudi Arabia* (1st ed. 2000. ed.). Springer US. https://doi.org/10.1007/b112322

Mulrow, C. D. (1994). Systematic Reviews: Rationale for systematic reviews. *BMJ, 309*(6954), 597-599. https://doi.org/10.1136/bmj.309.6954.597

Murray, E., Pollack, L., White, M., & Lo, B. (2007). Clinical decision-making: Patients' preferences and experiences. *Patient Education and Counseling, 65*(2), 189-196. https://doi.org/10.1016/j.pec.2006.07.007

Naeem, Z. (2015, Jul). Burden of Diabetes Mellitus in Saudi Arabia. *Int J Health Sci (Qassim), 9*(3), V-vi. https://doi.org/10.12816/0024690

Nam, S., Chesla, C., Stotts, N. A., Kroon, L., & Janson, S. L. (2011). Barriers to diabetes management: Patient and provider factors. *Diabetes research and clinical practice, 93*(1), 1-9. https://doi.org/10.1016/j.diabres.2011.02.002

Nancy Leopold, M., Cooper, J., & Clancy, C. (1996). Sustained partnership in primary care. *The Journal of family practice, 42*(2), 129.

National Center for Health, S. (2012). *Healthy People 2010 Final Review*. https://www.cdc.gov/nchs/data/hpdata2010/hp2010_final_review.pdf

Nayak, B. K., & Hazra, A. (2011). How to choose the right statistical test? *Indian Journal of Ophthalmology, 59*(2), 85. https://doi.org/10.4103/0301-4738.77005

Neff, M. J. (2008). Informed consent: what is it? Who can give it? How do we improve it? *Respiratory Care, 53*(10), 1337-1341.

Nimmon, L., & Stenfors-Hayes, T. (2016). The "Handling" of power in the physician-patient encounter: perceptions from experienced physicians. *BMC Medical Education, 16*(1), 1-9. https://doi.org/10.1186/s12909-016-0634-0

Nota, I., Drossaert, C. H. C., Taal, E., & Van De Laar, M. A. F. J. (2016). Arthritis patients' motives for (not) wanting to be involved in medical decision-making and the factors that hinder or promote patient involvement. *Clinical Rheumatology, 35*(5), 1225-1235. https://doi.org/10.1007/s10067-014-2820-y

Nouri, S. S., & Rudd, R. E. (2015). Health literacy in the "oral exchange": An important element of patient–provider communication. *Patient Education and Counseling, 98*(5), 565-571. https://doi.org/10.1016/j.pec.2014.12.002

O'Sullivan, A., Rey, M.-E., & Mendez, J. G. (2011). Opportunities and Challenges in the MENA Region. *Arab world competitiveness report, 2012*, 42-67.

Obeidat, R., & Khrais, H. I. (2016). Jordanian physicians' attitudes toward disclosure of cancer information and patient participation in treatment decision-making. *Asia-Pacific journal of oncology nursing, 3*(3), 281-288. https://doi.org/10.4103/2347-5625.189811

Obeidat, R., & Lally, R. (2018). Jordanian physicians' perceived barriers and facilitators to patient participation in treatment decision-making: An exploratory study. *Indian journal of cancer, 55*(4), 377-381. https://doi.org/10.4103/ijc.IJC_122_18

Obilor, E. I., & Amadi, E. C. (2018). Test for significance of Pearson's correlation coefficient. *International Journal of Innovative Mathematics, Statistics & Energy Policies, 6*(1), 11-23.

Ocloo, J., Garfield, S., Franklin, B. D., & Dawson, S. (2021). Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews. *Health Research Policy and Systems, 19*(1). https://doi.org/10.1186/s12961-020-00644-3

Odeh Yosef, A. R. (2008). Health Beliefs, Practice, and Priorities for Health Care of Arab Muslims in the United States. *Journal of transcultural nursing, 19*(3), 284-291. https://doi.org/10.1177/1043659608317450

Olesen, K., Folmann Hempler, N., Drejer, S., Valeur Baumgarten, S., & Stenov, V. (2020). Impact of patient-centred diabetes self-management education targeting people with type 2 diabetes: an integrative review [Review]. *Diabetic medicine, 37*(6), 909-923. https://doi.org/10.1111/dme.14284

Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2023, 2023/03/04). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher, 45*(3), 241-251. https://doi.org/10.1080/0142159X.2022.2057287

Onwuegbuzie, A. J., & Leech, N. L. (2007). Validity and Qualitative Research: An Oxymoron? *Quality & Quantity, 41*(2), 233-249. https://doi.org/10.1007/s11135-006-9000-3

Padela, A. I., & Del Pozo, P. R. (2011). Muslim patients and cross-gender interactions in medicine: an Islamic bioethical perspective. *Journal of Medical Ethics, 37*(1), 40-44. https://doi.org/10.1136/jme.2010.037614

Paiva, D., Abreu, L., Azevedo, A., & Silva, S. (2019). Patient-centered communication in type 2 diabetes: The facilitating and constraining factors in clinical encounters. *Health services research, 54 3*, 623-635. https://doi.org/10.1111/1475-6773.13126

Pallant, J. (2020). *SPSS survival manual : a step by step guide to data analysis using IBM SPSS* (7th edition. ed.). ALLEN and UNWIN.

Park, M., Giap, T.-T.-T., Lee, M., Jeong, H., Jeong, M., & Go, Y. (2018). Patient- and family-centered care interventions for improving the quality of health care: A review of systematic reviews. *International journal of nursing studies, 87*, 69-83. https://doi.org/10.1016/j.ijnurstu.2018.07.006

Parkash, J., Younis, M. Z., & Ward, W. (2015). Healthcare for the Ageing Populations of Countries of Middle East and North Africa. *Ageing international, 40*(1), 3-12. https://doi.org/10.1007/s12126-012-9150-7

Parveen, H., & Showkat, N. (2017). Research Ethics.

Paul, C., & Brookes, B. (2015). The Rationalization of Unethical Research: Revisionist Accounts of the Tuskegee Syphilis Study and the New Zealand "Unfortunate Experiment". *American journal of public health (1971), 105*(10), e12-e19. https://doi.org/10.2105/AJPH.2015.302720

Peek, M. E., Quinn, M. T., Gorawara-Bhat, R., Odoms-Young, A., Wilson, S. C., & Chin, M. H. (2008). How is shared decision-making defined among African-Americans with diabetes? *Patient Education and Counseling, 72*(3), 450-458. https://doi.org/10.1016/j.pec.2008.05.018

Peek, M. E., Wilson, S. C., Gorawara-Bhat, R., Odoms-Young, A., Quinn, M. T., & Chin, M. H. (2009). Barriers and Facilitators to Shared Decision-making Among African-Americans with Diabetes. *Journal of general internal medicine : JGIM, 24*(10), 1135-1139. https://doi.org/10.1007/s11606-009-1047-0

Peimani, M., Nasli-Esfahani, E., & Sadeghi, R. (2020). Patients' perceptions of patient–provider communication and diabetes care: A systematic review of quantitative and qualitative studies. *Chronic Illness, 16*(1), 3-22. https://doi.org/10.1177/1742395318782378

Pereira, L., Figueiredo-Braga, M., & Carvalho, I. P. (2016). Preoperative anxiety in ambulatory surgery: The impact of an empathic patient-centered approach on psychological and clinical outcomes. *Patient Education and Counseling, 99*(5), 733-738. https://doi.org/10.1016/j.pec.2015.11.016

Peters, M. D., Godfrey, C. M., Khalil, H., McInerney, P., Parker, D., & Soares, C. B. (2015). Guidance for conducting systematic scoping reviews. *JBI Evidence Implementation, 13*(3), 141-146. https://doi.org/10.1097/XEB.0000000000000050

Petticrew, M., & Roberts, H. (2006). *Systematic reviews in the social sciences : a practical guide*. Blackwell Pub.

Petticrew, M., & Roberts, H. (2006). Why Do We Need Systematic Reviews? In *Systematic Reviews in the Social Sciences* (pp. 1-26). https://doi.org/https://doi.org/10.1002/9780470754887.ch1

Picker Institute. (2021). *Principles of Person Centred Care*. https://www.picker.org/about-us/picker-principles-of-person-centred-care/

Pieterse, A. H., Brandes, K., de Graaf, J., de Boer, J. E., Labrie, N. H. M., Knops, A., Allaart, C. F., Portielje, J. E. A., Bos, W. J. W., & Stiggelbout, A. M. (2022). Fostering Patient Choice Awareness and Presenting Treatment Options Neutrally: A Randomized Trial to Assess the Effect on Perceived Room for Involvement in Decision Making. *Medical Decision Making, 42*(3), 375-386. https://doi.org/10.1177/0272989x211056334

Planetree. (2021). *Planetree Person-Centered Care Certified Sites*. Retrieved 30 May 2023 from https://planetree.org/planetree-person-centered-care-certified-sites/

Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principles and methods*. Lippincott Williams & Wilkins.

Polit, D. F., & Beck, C. T. (2017). *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. Wolters Kluwer Health.

Pomey, M.-P., Denis, J.-L., & Dumez, V. (2019). From Medical Paternalism to Care Partnerships: A Logical Evolution Over Several Decades. In *Patient Engagement How Patient-provider Partnerships Transform Healthcare Organizations* (pp. 9-16). Springer International Publishing AG. https://doi.org/10.1007/978-3-030-14101-1_2

Pomey, M.-P., Dumez, V., Boivin, A., Rouly, G., Lebel, P., Berkesse, A., Descoteaux, A., Jackson, M., Karazivan, P., & Clavel, N. (2019). The Participation of Patients and Relatives in Quebec's Health System: The Montréal Model. In (pp. 17-61). Springer International Publishing. https://doi.org/10.1007/978-3-030-14101-1_3

Pomey, M.-P., Ghadiri, D. P., Karazivan, P., Fernandez, N., & Clavel, N. (2015). Patients as partners: a qualitative study of patients' engagement in their health care. *PLOS ONE, 10*(4), e0122499-e0122499. https://doi.org/10.1371/journal.pone.0122499

Pomey, M.-P., Hihat, H., Khalifa, M., Lebel, P., Néron, A., & Dumez, V. (2015). Patient partnership in quality improvement of healthcare services: Patients' inputs and challenges faced. *Patient experience journal, 2*(1), 29-42. https://doi.org/10.35680/2372-0247.1064

Pulvirenti, M., McMillan, J., & Lawn, S. (2014). Empowerment, patient centred care and self-management. *Health expectations : an international journal of public participation in health care and health policy, 17*(3), 303-310. https://doi.org/10.1111/j.1369-7625.2011.00757.x

Qidwai, W. (2003). Paternalistic model of medical practice. *Journal of College of Physicians and Surgeons Pakistan, 13*(5), 296.

Rafiei, S., Pourreza, A., Kazemzadeh, R. B., & Jahantigh, F. F. (2013). Evaluation of power distance and Its consequences on hospitals of Tehran University of Medical Sciences. *American Journal of Public Health Research, 1*(3), 59-64. https://doi.org/10.12691/ajphr-1-3-1

Rahem, A., Utami, W., Sukorini, A. I., & Effendi, M. H. (2019). The Effect of Advocacy on Understanding and Levels of Blood Glucose in Diabetes Mellitus Patients. *Asian Journal of Pharmaceutics (AJP), 13*(4), 375-380. https://doi.org/10.22377/ajp.v13i04.3411

Rahman, R. (2020). The Privatization of Health Care System in Saudi Arabia. *Health Services Insights, 13*, 1-8. https://doi.org/10.1177/1178632920934497

Rahman, R., & Al-Borie, H. M. (2021). Strengthening the Saudi Arabian healthcare system: role of vision 2030. *International Journal of Healthcare Management, 14*(4), 1483-1491. https://doi.org/10.1080/20479700.2020.1788334

Rahman, R., & Alsharqi, O. Z. (2019). What drove the health system reforms in the Kingdom of Saudi Arabia? An analysis. *The International journal of health planning and management, 34*(1), 100-110. https://doi.org/10.1002/hpm.2584

Rahman, R., Matthews, E. B., Ahmad, A., Rizvi, S. M., Salama, U., Samad, L., & Khan, M. (2019). Perceptions of patient-centred care among providers and patients in the orthopaedic department of a tertiary care hospital in Karachi, Pakistan. *Journal of evaluation in clinical practice, 25*(6), 1160-1168. https://doi.org/10.1111/jep.13242

Raja, S., Hasnain, M., Vadakumchery, T., Hamad, J., Shah, R., & Hoersch, M. (2015). Identifying Elements of Patient-Centered Care in Underserved Populations: A Qualitative Study of Patient Perspectives. *PLOS ONE, 10*(5), e0126708. https://doi.org/10.1371/journal.pone.0126708

Rajaram, S. S., & Rashidi, A. (1999). Asian-Islamic Women and Breast Cancer Screening: A Socio-Cultural Analysis. *Women & Health, 28*(3), 45-58. https://doi.org/10.1300/j013v28n03_04

Rao, J. K., Anderson, L. A., Inui, T. S., & Frankel, R. M. (2007). Communication Interventions Make a Difference in Conversations between Physicians and Patients: A Systematic Review of the Evidence. *Medical care, 45*(4), 340-349. https://doi.org/10.1097/01.mlr.0000254516.04961.d5

Rasha, A.-B., Benjamin, B., Saad, A.-S., & Samuel, J. S. (2009). Cross-cultural comparison of the patient-centeredness of the hidden curriculum between a Saudi Arabian and 9 US medical schools. *Medical education online, 14*(1), 19. https://doi.org/10.3402/meo.v14i.4655

Rassouli, M., Zamanzadeh, V., Valizadeh, L., Ghahramanian, A., & Asghari, E. (2020). Limping along in implementing patient-centered care: Qualitative study. *Nursing practice today, 7*(3). https://doi.org/10.18502/npt.v7i3.3350

Rathert, C., Wyrwich, M. D., & Boren, S. A. (2013). Patient-Centered Care and Outcomes: A Systematic Review of the Literature. *Medical care research and review, 70*(4), 351-379. https://doi.org/10.1177/1077558712465774

Ratna, H. (2019). The Importance of Effective Communication in Healthcare Practice. *Harvard Public Health Review, 23*, 1-6. https://www.jstor.org/stable/48546767

Rawaf, S., Amati, F., McDonald, A., Majeed, A., & Dubois, E. (2011). Implementation and evaluation of patient-centred care in experimental studies from 2000-2010: systematic review. *International Journal of Person Centered Medicine, 1*(2), 348-357. https://doi.org/10.5750/ijpcm.v1i2.77

Rebekić, A., Lončarić, Z., Petrović, S., & Marić, S. (2015). PEARSON'S OR SPEARMAN'S CORRELATION COEFFICIENT - WHICH ONE TO USE? *Poljoprivreda, 21*(2), 47-54. https://doi.org/10.18047/poljo.21.2.8

Rehman, A. A., & Alharthi, K. (2016). An introduction to research paradigms. *International Journal of Educational Investigations, 3*(8), 51-59.

Rehman, H., Ahmed, Z., Hashmi, F., & Jamil, K. (2017). Challenging status about patient centricity among health care profession in Pakistan. *Rawal Medical Journal, 42*(3), 414-420.

Reynolds, A. (2009). Patient-centered Care. *Radiologic Technology, 81*(2), 133-147.

Richardson, W. C., Berwick, D. M., Bisgard, J., Bristow, L., Buck, C., & Cassel, C. (2001). *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: National Academy Press.

Rider, E. A., & Keefer, C. H. (2006). Communication skills competencies: definitions and a teaching toolbox. *Medical education, 40*(7), 624-629. https://doi.org/10.1111/j.1365-2929.2006.02500.x

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). *Qualitative research practice: A guide for social science students and researchers*. sage.

Roberti Di Sarsina, P., & Tassinari, M. (2015). Person-centred healthcare and medicine paradigm: it's time to clarify. *EPMA Journal, 6*(1). https://doi.org/10.1186/s13167-015-0033-3

Robinson, J. H., Callister, L. C., Berry, J. A., & Dearing, K. A. (2008). Patient-centered care and adherence: Definitions and applications to improve outcomes. *Journal of the American Academy of Nurse Practitioners, 20*(12), 600-607. https://doi.org/10.1111/j.1745-7599.2008.00360.x

Rodríguez, J. D., Paucar, J., & Bedoya, M. (2011). Overcoming misperceptions through intercultural education: Promoting the understanding between Colombia and the Middle East and North Africa (MENA). *Negocios Internacionales, 4*(1), 72-85.

Rose, S. L. (2013). Patient Advocacy Organizations: Institutional Conflicts of Interest, Trust, and Trustworthiness. *Journal of Law, Medicine & Ethics, 41*(3), 680-687. https://doi.org/10.1111/jlme.12078

Rosland, A.-M., Heisler, M., Choi, H.-J., Silveira, M. J., & Piette, J. D. (2010). Family influences on self-management among functionally independent adults with diabetes or heart failure: do family members hinder as much as they help? *Chronic Illness, 6*(1), 22-33. https://doi.org/10.1177/1742395309354608

Roumie, C. L., Greevy, R., Wallston, K. A., Elasy, T. A., Kaltenbach, L., Kotter, K., Dittus, R. S., & Speroff, T. (2011). Patient centered primary care is associated with patient hypertension medication adherence. *Journal of behavioral medicine, 34*(4), 244-253. https://doi.org/10.1007/s10865-010-9304-6

Ryan, J., & Sysko, J. (2007). The contingency of patient preferences for involvement in health decision making. *Health Care Management Review, 32*(1), 30-36. https://doi.org/10.1097/00004010-200701000-00005

Saad, A. M., Younes, Z. M., Ahmed, H., Brown, J. A., Al Owesie, R. M., & Hassoun, A. A. (2018). Self-efficacy, self-care and glycemic control in Saudi Arabian patients with type 2 diabetes mellitus: A cross-sectional survey. *Diabetes research and clinical practice, 137*, 28-36. https://doi.org/10.1016/j.diabres.2017.12.014

Saha, S., Beach, M. C., & Cooper, L. A. (2008, 2008/11/01/). Patient Centeredness, Cultural Competence and Healthcare Quality. *Journal of the National Medical Association, 100*(11), 1275-1285. https://doi.org/10.1016/S0027-9684(15)31505-4

Sainio, C., Eriksson, E., & Lauri, S. (2001). Patient participation in decision making about care: The cancer patient's point of view. *Cancer Nursing, 24*(3), 172-179. https://doi.org/10.1097/00002820-200106000-00002

Saleh Al Mutair, A., Plummer, V., Paul O'Brien, A., & Clerehan, R. (2014). Providing culturally congruent care for Saudi patients and their families. *Contemporary Nurse, 46*(2), 254-258. https://doi.org/10.5172/conu.2014.46.2.254

Sama'a, H. A., Alfayez, A. S., Alanazi, A. T., Alwuhaimed, L. A., & Hamed, S. S. B. (2021). Autonomy, accountability, and competition: the privatisation of the Saudi health care system. *Journal of Taibah University Medical Sciences, 16*(2), 144-151. https://doi.org/10.1016/j.jtumed.2020.11.005

Sandman, L., & Munthe, C. (2010). Shared Decision Making, Paternalism and Patient Choice. *Health care analysis, 18*(1), 60-84. https://doi.org/10.1007/s10728-008-0108-6

Santana, M. J., Manalili, K., Jolley, R. J., Zelinsky, S., Quan, H., & Lu, M. (2018). How to practice person-centred care: A conceptual framework. *Health expectations : an international journal of public participation in health care and health policy, 21*(2), 429-440. https://doi.org/10.1111/hex.12640

Saudi Central Bank. (2021). *57th Annual Report* (57). https://www.sama.gov.sa/en-US/EconomicReports/AnnualReport/ANNUAL_Report_57th_2021.pdf

Saudi Commission for Health Specialists. *UNDERSTANDING THE NEW MODEL OF CARE*. Retrieved 23 Oct 2023 from https://ha-learning.scfhs.org.sa/enrol/index.php?id=2846

Say, R., Murtagh, M., & Thomson, R. (2006). Patients' preference for involvement in medical decision making: A narrative review. *Patient Education and Counseling, 60*(2), 102-114. https://doi.org/10.1016/j.pec.2005.02.003

Schattner, A., Bronstein, A., & Jellin, N. (2006). Information and shared decision-making are top patients' priorities. *BMC Health Services Research, 6*(1), 21-21. https://doi.org/10.1186/1472-6963-6-21

Scholl, I., Zill, J. M., Härter, M., & Dirmaier, J. (2014). An integrative model of patient-centeredness - a systematic review and concept analysis. *PLOS ONE, 9*(9), e107828-e107828. https://doi.org/10.1371/journal.pone.0107828

Scholz, B., Bocking, J., & Happell, B. (2017, 2017/05/04). Breaking through the Glass Ceiling: Consumers in Mental Health Organisations' Hierarchies. *Issues in Mental Health Nursing, 38*(5), 374-380. https://doi.org/10.1080/01612840.2017.1280106

Scholz, B., Bocking, J., Platania-Phung, C., Banfield, M., & Happell, B. (2018, 2018/08/01/). "Not an afterthought": Power imbalances in systemic partnerships between health service providers and consumers in a hospital setting. *Health Policy, 122*(8), 922-928. https://doi.org/10.1016/j.healthpol.2018.06.007

Sebai, Z. A., Milaat, W. A., & Al-Zulaibani, A. A. (2001). Health care services in saudi arabia: past, present and future. *Journal of Family & Community Medicine, 8*(3), 19-23.

Shaller, D. (2007). *Patient-centered care: what does it take?* Commonwealth Fund New York.

Sharara, S. L., & Kanj, S. S. (2014). War and infectious diseases: challenges of the Syrian civil war. *PLoS Pathogens, 10*(11), e1004438. https://doi.org/10.1371/journal.ppat.1004438

Shawky, S. (2010). Primary health care in the Eastern Mediterranean Region: from Alma-Ata to Doha/Les soins de sante primaires dans la Region de la Mediterranee orientale: d'Alma-Ata a Doha. *Eastern Mediterranean health journal, 16*(12), 1285. https://doi.org/10.26719/2010.16.12.1285

Shawky, S., & Soliman, N. K. (2001). Going beyond the curriculum to promote medical education and practice in Saudi Arabia. *Saudi medical journal, 22*(6), 477-480.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*, 63-75. https://doi.org/10.3233/EFI-2004-22201

Shepherd, H. L., Tattersall, M. H. N., & Butow, P. N. (2008). Physician-Identified Factors Affecting Patient Participation in Reaching Treatment Decisions. *Journal of Clinical Oncology, 26*(10), 1724-1731. https://doi.org/10.1200/jco.2007.13.5566

Shibily, F. M., Aljohani, N. S., Aljefri, Y. M., Almutairi, A. S., Almutairi, W. Z., Alhallafi, M. A., Alsharif, F., Almutairi, W., & Badr, H. (2021). The Perceptions of Nurses and Nursing Students Regarding Family Involvement in the Care of Hospitalized Adult Patients. *Nursing reports (Pavia, Italy), 11*(1), 133-142. https://doi.org/10.3390/nursrep11010013

Shutzberg, M. (2021). The Doctor as Parent, Partner, Provider… or Comrade? Distribution of Power in Past and Present Models of the Doctor–Patient Relationship. *Health care analysis, 29*(3), 231-248. https://doi.org/10.1007/s10728-021-00432-2

Sidani, S., Soeren, M., Hurlock-Chorostecki, C., Reeves, S., Fox, M. T., & Collins, L. C. (2016). Health professionals and patient" perceptions of patient-centered care: a comparison. *European Journal for Person Centered Healthcare, 4*, 641-649.

Silbermann, M., Epner, D., Charalambous, H., Baider, L., Puchalski, C. M., Balducci, L., Gultekin, M., Abdalla, R., Daher, M., & Al-Tarawneh, M. (2013). Promoting new approaches for cancer care in the Middle East. *Annals of Oncology, 24*, vii5-vii10. https://doi.org/10.1093/annonc/mdt267

Silbermann, M., & Hassan, E. A. (2011). Cultural perspectives in cancer care: impact of Islamic traditions and practices in Middle Eastern countries. *Journal of pediatric hematology/oncology, 33 Suppl 2*(Supplement 2), S81-S86. https://doi.org/10.1097/MPH.0b013e318230dab6

Singh, O. N., Phillips, K. A., Rodriguez-Gutierrez, R., Castaneda-Guarderas, A., Gionfriddo, M. R., Branda, M. E., & Montori, V. M. (2019). Eliciting the patient's agenda-secondary analysis of recorded clinical encounters. *Journal of General Internal Medicine, 34*, 36-40. https://doi.org/doi.org/10.1007/s11606-018-4540-5

Smith, M. A. (2016). The role of shared decision making in patient-centered care and orthopaedics. *Orthopaedic Nursing, 35*(3), 144-149. https://doi.org/10.1097/NOR.0000000000000243

Smith, R., Martin, A., Wright, T., Hulbert, S., & Hatzidimitriadou, E. (2021). Integrated dementia care: A qualitative evidence synthesis of the experiences of people living with dementia, informal carers and healthcare professionals. *Archives of Gerontology and Geriatrics, 97*, 104471. https://doi.org/10.1016/j.archger.2021.104471

Spencer, J., Godolphin, W., Karpenko, N., & Towle, A. (2011). *Can patients be teachers? Involving patients and service users in healthcare professional's education* (Involving patients and service users in healthcare professionals' education, Issue. https://www.health.org.uk/publications/can-patients-be-teachers

Stewart, M., Brown, J. B., Donner, A., McWhinney, I. R., Oates, J., Weston, W. W., & Jordan, J. (2000). The impact of patient-centered care on outcomes. *The Journal of family practice, 49*(9), 796-804.

Stiggelbout, A. M., Pieterse, A. H., & De Haes, J. C. J. M. (2015). Shared decision making: Concepts, evidence, and practice. *Patient Education and Counseling, 98*(10), 1172-1179. https://doi.org/10.1016/j.pec.2015.06.022

Stone, S. (2008). A Retrospective Evaluation of the Impact of the Planetree Patient-Centered Model of Care on Inpatient Quality Outcomes. *HERD: Health Environments Research & Design Journal, 1*(4), 55-69. https://doi.org/10.1177/193758670800100406

Sultan, W. I. M., Sultan, M. I. M., & Crispim, J. (2018). Palestinian doctors' views on patient-centered care in hospitals. *BMC Health Services Research, 18*(1), 766-766. https://doi.org/10.1186/s12913-018-3573-0

Sürücü, L., & Maslakçi, A. (2020). VALIDITY AND RELIABILITY IN QUANTITATIVE RESEARCH. *Business & Management Studies: An International Journal, 8*(3), 2694-2726. https://doi.org/10.15295/bmij.v8i3.1540

Taherdoost, H. (2016). Validity and Reliability of the Research Instrument; How to Test the Validation of a Questionnaire/Survey in a Research. *SSRN Electronic Journal*. https://doi.org/10.2139/ssrn.3205040

Tait, R. C. (2008, April). Empathy: Necessary for effective pain management? *Current Pain and Headache Reports, 12(2)*, 108-112. https://doi.org/10.1007/s11916-008-0021-6

Tandon, A., Murray, C. J., Lauer, J. A., & Evans, D. B. (2000). Measuring overall health system performance for 191 countries. *Geneva: World Health Organization*.

Tariq, S., & Woodman, J. (2013). Using mixed methods in health research. *JRSM Short Reports, 4*(6), 2042533313479197. https://doi.org/10.1177/2042533313479197

Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International journal of medical education, 2*, 53-55. https://doi.org/10.5116/ijme.4dfb.8dfd

Taylor, K. (2009). Paternalism, participation and partnership—The evolution of patient centeredness in the consultation. *Patient Education and Counseling, 74*(2), 150-155. https://doi.org/10.1016/j.pec.2008.08.017

Taylor, S. L., & Lurie, N. (2004). The role of culturally competent communication in reducing ethnic and racial healthcare disparities. *The American journal of managed care, 10*, SP1-4.

Teddlie, C., & Yu, F. (2007). Mixed Methods Sampling: A Typology With Examples. *Journal of Mixed Methods Research, 1*(1), NP1-NP1. https://doi.org/10.1177/2345678906292430

Telmesani, A., Zaini, R. G., & Ghazi, H. O. (2011). Medical education in Saudi Arabia: a review of recent developments and future challenges / Enseignement medical en Arabie saoudite : revue des recentes evolutions et des defis a venir. *Eastern Mediterranean health journal, 17*(8), 703. https://doi.org/10.26719/2011.17.8.703

Temple-Oberle, C., Ayeni, O., Webb, C., Bettger-Hahn, M., Ayeni, O., & Mychailyshyn, N. (2014). Shared decision-making: Applying a person-centered approach to tailored breast reconstruction information provides high satisfaction across a variety of breast reconstruction options. *Journal of Surgical Oncology, 110*(7), 796-800. https://doi.org/10.1002/jso.23721

Terrien, J. M., & Hale, J. F. (2014). Patients as educators: Contemporary application of an old educational strategy to promote patient-centered care. *Journal of Nursing Education and Practice, 4*(4), 104. https://doi.org/10.5430/jnep.v4n4p104

The Australian Commission on Safety and Quality in Health Care. (2016). *Patient-clinician communication in hospitals*. Retrieved 6 Feb 2024 from

https://www.safetyandquality.gov.au/sites/default/files/migrated/Information-sheet-for-healthcare-providers-Improving-patient-clinician-communication.pdf

The Australian Patients Association. (2021). *Who we are. What we do.* Retrieved 23 December 2023 from https://www.patients.org.au/our-story/

The Health Foundation. (2023). *About the Health Foundation*. Retrieved 11 November 2023 from https://www.health.org.uk/about-the-health-foundation

The Ministry of Health. (2019). *Health Sector Transformation Strategy* MoH. Retrieved May 5, 2021 from https://www.moh.gov.sa/en/Ministry/vro/Documents/Healthcare-Transformation-Strategy.pdf

Thomasma, D. C. (1983). Beyond medical paternalism and patient autonomy: a model of physician conscience for the physician-patient relationship. *Annals of Internal Medicine, 98*(2), 243-248. https://doi.org/10.7326/0003-4819-98-2-243

Tiliouine, H., & Meziane, M. (2017). The History of Well-Being in the Middle East and North Africa (MENA). In *The Pursuit of Human Well-Being, International Handbooks of Quality-of-Life* (pp. 523-563). Springer International Publishing. https://doi.org/10.1007/978-3-319-39101-4_16

Ting, X., Yong, B., Yin, L., & Mi, T. (2016). Patient perception and the barriers to practicing patient-centered communication: A survey and in-depth interview of Chinese patients and physicians. *Patient Education and Counseling, 99*(3), 364-369. https://doi.org/10.1016/j.pec.2015.07.019

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care, 19*(6), 349-357. https://doi.org/10.1093/intqhc/mzm042

Topaz, M., Bar-Bachar, O., Admi, H., Denekamp, Y., & Zimlichman, E. (2020). Patient-centered care via health information technology: a qualitative study with experts from Israel and the U.S. *Informatics for health & social care, 45*(3), 217-228. https://doi.org/10.1080/17538157.2019.1582055

Travaline, J. M., Ruchinskas, R., & D'Alonzo, G. E. (2005). Patient-Physician Communication: Why and How. *105*(1), 13-18. https://doi.org/10.7556/jaoa.2005.105.1.13 (Journal of Osteopathic Medicine)

Tsianakas, V., & Liamputtong, P. (2002). What women from an Islamic background in Australia say about care in pregnancy and prenatal testing. *Midwifery, 18*(1), 25-34. https://doi.org/10.1054/midw.2002.0296

Tu, J., Kang, G., Zhong, J., & Cheng, Y. (2019). Outpatient communication patterns in a cancer hospital in China: a qualitative study of doctor–patient encounters. *Health Expectations, 22*(3), 594-603. https://doi.org/10.1111/hex.12890

Tutton, E. M. M. (2005). Patient participation on a ward for frail older people. *Journal of advanced nursing, 50*(2), 143-152. https://doi.org/10.1111/j.1365-2648.2005.03373.x

Tyrovolas, S., El Bcheraoui, C., Alghnam, S. A., Alhabib, K. F., Almadi, M. A. H., Al-Raddadi, R. M., Bedi, N., El Tantawi, M., Krish, V. S., & Memish, Z. A. (2020). The burden of disease in Saudi Arabia 1990–2017: results from the Global Burden of Disease Study 2017. *The Lancet Planetary Health, 4*(5), e195-e208. https://doi.org/10.1016/S2542-5196(20)30075-9

Uhlmann, R. F., Inui, T. S., & Carter, W. B. (1984). Patient Requests and Expectations: Definitions and Clinical Applications. *Medical care, 22*(7), 681-685. http://www.jstor.org/stable/3764628

Ulin, K., Malm, D., & Nygårdh, A. (2015). What Is Known About the Benefits of Patient-Centered Care in Patients with Heart Failure. *Current heart failure reports, 12*(6), 350-359. https://doi.org/10.1007/s11897-015-0272-6

Vahdat, S., Hamzehgardeshi, L., Hessam, S., & Hamzehgardeshi, Z. (2014). Patient Involvement in Health Care Decision Making: A Review. *Iranian Red Crescent Medical Journal, 16*(1). https://doi.org/10.5812/ircmj.12454

Vainio, A. (2013). Beyond research ethics: Anonymity as 'ontology','analysis' and 'independence'. *Qualitative Research, 13*(6), 685-698. https://doi.org/10.1177/1468794112459669

Vakil, K., Desse, T. A., Manias, E., Alzubaidi, H., Rasmussen, B., Holton, S., & Mc Namara, K. P. (2023). Patient-Centered Care Experiences of First-Generation, South Asian Migrants with Chronic Diseases Living in High-Income, Western Countries: Systematic Review. *Patient preference and adherence*, 281-298. https://doi.org/10.2147/PPA.S391340

Van Bommel, M. (2011). *Expatriate non-Muslim nurses' experiences of working in a cardiac intensive care unit in Saudi Arabia* [Master, University of South Africa]. Pretoria.

Vanderboom, C. E., Holland, D. E., Lohse, C. M., Targonski, P. V., & Madigan, E. A. (2014). Enhancing patient-centered care: pilot study results of a community care team intervention. *Western journal of nursing research, 36*(1), 47-65. https://doi.org/10.1177/0193945913490841

Vanderstoep, S. W., & Johnson, D. D. (2008). *Research methods for everyday life: Blending qualitative and quantitative approaches* (Vol. 32). John Wiley & Sons.

Vennedey, V., Hower, K. I., Hillen, H., Ansmann, L., Kuntz, L., & Stock, S. (2020). Patients' perspectives of facilitators and barriers to patient-centred care: insights from qualitative patient interviews. *BMJ open, 10*(5), e033449. https://doi.org/10.1136/bmjopen-2019-033449

Vijn, T. W., Wollersheim, H., Faber, M. J., Fluit, C., & Kremer, J. A. M. (2018). Building a patient-centered and interprofessional training program with patients, students and care professionals: study protocol of a participatory design and evaluation study

[Research Support, Non-U.S. Gov't]. *BMC Health Services Research, 18*(1), 387. https://doi.org/10.1186/s12913-018-3200-0

Ward, J., Cody, J., Schaal, M., & Hojat, M. (2012). The empathy enigma: an empirical study of decline in empathy among undergraduate nursing students. *Journal of Professional Nursing, 28*(1), 34-40. https://doi.org/10.1016/j.profnurs.2011.10.007

Warde, F., Papadakos, J., Papadakos, T., Rodin, D., Salhia, M., & Giuliani, M. (2018, May). Plain language communication as a priority competency for medical professionals in a globalized world. *Can Med Educ J, 9*(2), e52-e59. https://doi.org/10.36834/cmej.36848

Weaver, K., & Olson, J. K. (2006). Understanding paradigms used for nursing research. *Journal of advanced nursing, 53*(4), 459-469. https://doi.org/10.1111/j.1365-2648.2006.03740.x

Weaver, K. F., Morales, V., Dunn, S. L., Godde, K., & and Weaver, P. F. (2017a). ANOVA. In *An Introduction to Statistical Analysis in Research* (pp. 227-296). https://doi.org/10.1002/9781119454205.ch6

Weaver, K. F., Morales, V., Dunn, S. L., Godde, K., & and Weaver, P. F. (2017b). t-Test. In *An Introduction to Statistical Analysis in Research* (pp. 195-225). https://doi.org/10.1002/9781119454205.ch5

Weaver, K. F., Morales, V., Dunn, S. L., Godde, K. , & and Weaver, P. F. (2017). Pearson's and Spearman's Correlation. In *An Introduction to Statistical Analysis in Research* (pp. 435-471). https://doi.org/10.1002/9781119454205.ch10

Webair, H. H. (2020). Patient-Centered Care in the Middle East. In I. Laher (Ed.), *Handbook of Healthcare in the Arab World* (2020// ed., pp. 1-17). Springer International Publishing. https://doi.org/10.1007/978-3-319-74365-3_66-1

Wells, N. M. (2011). Historical Perspective on Family-Centered Care. *Academic Pediatrics, 11*(2), 100-102. https://doi.org/10.1016/j.acap.2011.01.007

Wheeldon, J. (2010). Mapping mixed methods research: Methods, measures, and meaning. *Journal of Mixed Methods Research, 4*(2), 87-102. https://doi.org/10.1177/1558689809358755

Wiles, R., Crow, G., Heath, S., & Charles, V. (2008). The Management of Confidentiality and Anonymity in Social Research. *International Journal of Social Research Methodology, 11*(5), 417-428. https://doi.org/10.1080/13645570701622231

Williams, J. S., Walker, R. J., Smalls, B. L., Hill, R., & Egede, L. E. (2016). Patient-Centered Care, Glycemic Control, Diabetes Self-Care, and Quality of Life in Adults with Type 2 Diabetes. *Diabetes Technology & Therapeutics, 18*(10), 644-649. https://doi.org/10.1089/dia.2016.0079

Woodman, A., Waheed, K. B., Rasheed, M., & Ahmad, S. (2022). Current state of ethical challenges reported in Saudi Arabia: a systematic review & bibliometric analysis from

2010 to 2021. *BMC Medical Ethics, 23*(1). https://doi.org/10.1186/s12910-022-00816-6

World Health Organization. (1978). *Declaration of Alma-Ata: International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978*. www.who.int/docs/default-source/documents/almaata-declaration-en.pdf

World Health Organization. (1998). *Health promotion glossary* (WHO/HPR/HEP/98.1). https://iris.who.int/bitstream/handle/10665/64546/WHO_HPR_HEP_98.1.pdf?sequence=1

World Health Organization. (1999). *Definition, diagnosis and classification of diabetes mellitus and its complications: report of a WHO consultation. Part 1, Diagnosis and classification of diabetes mellitus*. https://apps.who.int/iris/handle/10665/66040

World Health Organization. (2007a). *PEOPLE AT THE CENTRE OF CARE INITIATIVE*. /https://iris.who.int/bitstream/handle/10665/357429/WPR_RC058_Res04_2007_en.pdf

World Health Organization. (2007b). *People-centred health care : a policy framework*. WHO Regional Office for the Western Pacific. http://iris.wpro.who.int/handle/10665.1/5420 https://apps.who.int/iris/handle/10665/206971

World Health Organization. (2016a). *Framework on integrated, people-centred health services*.

World Health Organization. (2016b). Patient engagement.

World Health Organization. (2016c). *World Health Organization Global Report on Diabetes* (Geneva: World Health Organization, Issue. https://www.who.int/publications/i/item/9789241565257

World Health Organization. (2018). *Noncommunicable diseases country profiles 2018* (9241514620). W. H. Organization. https://apps.who.int/iris/handle/10665/274512

World Health Organization. (2020). *Noncommunicable Diseases Progress Monitor 2020* (978 92 4 000049 0). https://www.who.int/publications/i/item/ncd-progress-monitor-2020

Wubben, N., Van Den Boogaard, M., Van Der Hoeven, J., & Zegers, M. (2021). Shared decision-making in the ICU from the perspective of physicians, nurses and patients: a qualitative interview study. *BMJ open, 11*(8), e050134. https://doi.org/10.1136/bmjopen-2021-050134

Wylie, J. L., & Wagenfeld-Heintz, E. (2004). Development of Relationship-Centered Care. *Journal For Healthcare Quality, 26*(1), 14-21. https://doi.org/10.1111/j.1945-1474.2004.tb00467.x

Yasein, N. A., Shakhatreh, F. M., Shroukh, W. A., Farah, M. S., & Jaber, R. M. (2017). A Comparison between patients' and residents' perceptions of patient centeredness and

communication skills among physicians working at Jordan University Hospital. *Open Journal of Nursing, 7*(6), 698-706. https://doi.org/10.4236/ojn.2017.76052

Yates, J. F., & De Oliveira, S. (2016). Culture and decision making. *Organizational Behavior and Human Decision Processes, 136*, 106-118. https://doi.org/10.1016/j.obhdp.2016.05.003

Younas, M., Bradley, E., Holmes, N., Sud, D., & Maidment, I. D. (2016). Mental health pharmacists views on shared decision-making for antipsychotics in serious mental illness. *International Journal of Clinical Pharmacy, 38*(5), 1191-1199. https://doi.org/10.1007/s11096-016-0352-z

Zhao, J., Gao, S., Wang, J., Liu, X., & Hao, Y. (2016). Differentiation between two healthcare concepts: Person-centered and patient-centered care. *J Nurs, 2352*(0132), 10.1016. https://doi.org/10.1016/j.ijnss.2016.08.009

Zill, J. M., Scholl, I., Härter, M., & Dirmaier, J. (2015). Which dimensions of patient-centeredness matter?-Results of a web-based expert delphi survey. *PLOS ONE, 10*(11), e0141978. https://doi.org/10.1371/journal.pone.0141978

Zimmerman, G. M., Savage, L. M., Chandler, D. C., & Maccarone Buonfigli, M. (2005, Mar). Psoriatic arthritis and psoriasis: role of patient advocacy organisations in the twenty first century. *Ann Rheum Dis, 64 Suppl 2*(Suppl 2), ii93-100. https://doi.org/10.1136/ard.2004.033225

Zisman-Ilani, Y., Obeidat, R., Fang, L., Hsieh, S., & Berger, Z. (2020). Shared decision making and patient-centered care in Israel, jordan, and the united states: Exploratory and comparative survey study of physician perceptions. *JMIR formative research, 4*(8), e18223. https://doi.org/10.2196/18223

Zolfaghari, M., Asgari, P., Bahramnezhad, F., AhmadiRad, S., & Haghani, H. (2015). Comparison of two educational methods (family-centered and patient-centered) on hemodialysis: Related complications. *Iranian journal of nursing and midwifery research, 20*(1), 87-92.

APPENDIX A

The University of Sydney Ethical Approval

Thursday, 5 August 2021

Assoc Prof Jennifer Smith-Merry
Health Systems and Global Populations; Faculty of Medicine and Health
Email: jennifer.smith-merry@sydney.edu.au

Dear Jennifer,

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

I am pleased to inform you that after consideration of your response, your project has been approved.

Details of the approval are as follows:

Project No.:	**2021/530**
Project Title:	**How can patients contribute to developing the healthcare system in Saudi Arabia**
Authorised Personnel:	**Smith-Merry Jennifer; Alkhaibari Reeham; Forsyth Rowena; Alasmari Hajar;**
Approval Period:	**05/08/2021** to **05/08/2025**
First Annual Report Due:	**05/08/2022**

Documents Approved:

Date Uploaded	Version Number	Document Name
03/08/2021	Version 2	Participant Information Statement
18/06/2021	Version 2	Patient Flyer_v2
11/06/2021	Version 1	Recruitment Invitation Email
11/06/2021	Version 1	Recruitment Invitation Social Media
03/06/2021	Version 1	Patient Survey
03/06/2021	Version 1	Health Care Providers Survey
03/06/2021	Version 1	Interview Questions
03/06/2021	Version 1	Health Care Provider Information Statement
03/06/2021	Version 1	Safety Protocol
03/06/2021	Version 1	Patient Consent Form

Special Condition/s of Approval

- It will be a condition of approval that certified translations of the public documents (e.g. Participant Information Statement, Participant Consent Form) are made and provided to participants, once the English versions of the documents have been approved by the Ethics Office. Please refer to information on our Human Ethics website Translated documents for more information on how to ensure translations are appropriately certified.

- It will be a condition of approval that ethics approval from an appropriate authority in Saudi Arabia be obtained before any research activity is to commence. Evidence of this approval does not need to be submitted to the ethics office but should remain on file in case of audit.

Condition/s of Approval

- Research must be conducted according to the approved proposal.

- An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.
- You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
  - Serious or unexpected adverse events (which should be reported within 72 hours).
  - Unforeseen events that might affect continued ethical acceptability of the project.
- Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.
- Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.
- Data and primary materials must be retained and stored in accordance with the relevant legislation and University guidelines.
- Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.
- The Ethics Office may conduct audits on approved projects.
- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

This letter constitutes ethical approval only.

Please contact the Ethics Office should you require further information or clarification.

Sincerely,

Dr Kathryn Bartimote
Deputy Chair, Human Research Ethics Committee (HREC 2)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2018) and the NHMRC's Australian Code for the Responsible Conduct of Research (2018)

APPENDIX B

Saudi Arabia Directorate of Health Affairs Ethical approval

' Ethical approval '

IRB Registration Number With KACST , KSA: HAP-02-T-067
Approval number : 596
Date : 17/08/2021

Dear researcher`s

	Researcher's Name	Researcher's Character
1	Smith-Merry Jennifer	Research Supervisor
2	Reeham Alkhaibari	Principal Investigator

I am pleased to inform you submission dated **(01.SEP.2021)** for the study titled , **"How can patients contribute to developing the healthcare system in Saudi Arabia"**, was reviewed and was approved. please note that this approval is from the research ethics perspective only. you will still need to get permission from the manager of hospital or an external institution to commence data collection.

we wish you well as you proceed with the study and request you to keep the IRB informed of the progress on a regular basis , using the IRB log number shown above.

PLEASE BE ADVISED that regulations require that you submit a progress report on your research every 1 month, you are also required to submit any manuscript resulting from this research for approval by IRB before submission to journals for publication.

Best regards,,,,

Nabil mohammed al-thobiti
Director of Research and Studies Department

APPENDIX C

Participant Information Statement (patient)

[English version]

THE UNIVERSITY OF SYDNEY

Discipline of Behavioural and Social Sciences in Health
School of Health Science
Faculty of Medicine and Health

ABN 15 211 513 464

CHIEF INVESTIGATOR Jennifer Smith-Merry
Associate Professor
Head of Discipline Behavioural and Social Sciences in Health
Director of the Centre for Disability Research and Policy

Susan Wakil Health Building
The University of Sydney
NSW 2006 AUSTRALIA
Telephone: +61 0451943042
Email: ralk6229@uni.sydney.edu.au
Web: http://www.sydney.edu.au/

HOW CAN PATIENTS CONTRIBUTE TO DEVELOPING THE HEALTHCARE SYSTEM IN SAUDI ARABIA?

Diabetic patients

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in a research study about exploring patient involvement in the healthcare system in Saudi Arabia, understand the degree to which physicians can work with patients to enhance this involvement and finally, to contribute to the policies guiding patient involvement in the healthcare system in the kingdom

You have been invited to participate in this study because your participation will help us to gain a better understanding of how patients such as yourself experience involvement with decision making around the healthcare services you receive, particularly the cooperation between patients and physicians. The results will be used to develop strategies to improve patient involvement through developing policy and practice recommendations for patient involvement in Saudi Arabia. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

The study is being carried out by the following researchers:

- Reeham Ahmed Alkhaiari, PhD candidate at the University of Sydney.
- Associate Professor Jen Smith-Merry, The University of Sydney

- Dr Rowena Forsyth, The University of Sydney
- Dr Hajar Ali M Alasmari, Taif University

Reeham Ahmed Alkhaibari is conducting this study as the basis for the degree of PhD at The University of Sydney. This will take place under the supervision of Dr. Jennifer Smith-Merry and Dr. Rowena Forsyth

This study is being funded by Taif University, Kingdom of Saudi Arabia

(3) What will the study involve for me?

This study involves two steps: 1) an online questionnaire and, if you choose 2) an interview. Your participation in both the questionnaire and the interview are completely voluntary.

You will be eligible to participate in the study if you are living with diabetes and receiving care in a diabetic centre in Saudi Arabia. You will be asked to take a part in an online questionnaire and an interview. The online questionnaire will consist of two part, the first part is demographic characteristics which include (gender, age, level of education, occupation, marital status, level of education, health status). The second part will consist of 16 items of patient interaction with the healthcare providers.

If you wish to continue to patriciate in an interview, you can indicate your wish to do so at the end of the online questionnaire. We will then contact you to pass on further information about the interview and if you agree to participate, arrange a time for the interview.

The focus of the interview will be on your experience and expectation of involvement in health care decision making. The interview will be audio recorded to ensure accuracy of your perspectives. There will be no interpreter because the interviewer Reeham Alkhaibari can speak both Arabic and English fluently.

(4) How much of my time will the study take?

If you choose to participate in the study, you will be asked to participate in an online questionnaire that will take approximately 5-10 minutes to complete.
If you also agreed to participate in an interview, it will take approximately 30 minutes to 1 hour to complete.

(5) Who can take part in the study?

You are eligible to participate in the study if you meet the following criteria.

You will be eligible to take part in the study if you are:
- aged between 18 years – 80 years old.
- living with type 1 or type 2 diabetes mellitus for 2 years or more.
- Receiving care at a diabetic centre in Saudi Arabia
- Speak Arabic or English

You will be not eligible to participate in the study if you
- Have a condition that impairs your communication such as a hearing impairment or speech dysfunction as we do not have funding available for translation.

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you are not required to take apart in the study. Moreover, your decision whether to participate or not will not affect your current or future relationship with the researchers, your health care professionals or Taif University.

For the online questionnaire, submitting your completed questionnaire is an indication of your consent to participate in the study. You can withdraw your responses any time before you have submitted the questionnaire. Once you have submitted it, your responses cannot be withdrawn because they are anonymous and therefore, we will not be able to tell which one is yours. Submitting your completed questionnaire is an indication of your consent to participate in the study.

For the interview, participating in the interview is completely voluntary, you can withdraw consent to participate until the interview is complete and we will erase all information collected until that point. You may also refuse to answer any questions that you do not wish to answer during the interview. After the interview is complete you will not be able to withdraw as recordings will be erased and transcripts anonymised.

If you decide to take part in the study and then change your mind later, you are free to withdraw until 2 weeks after the interview. After that time the interview transcription will be complete and recordings erased. Up until this point you can withdraw by contacting the student researcher Reeham Ahmed Alkhaibari via email ralk6229@uni.sydney.edu.au and expressing your wish to withdraw from the study.

(7) Are there any risks or costs associated with being in the study?

Aside from giving up you time, we do not expect that there will be any risks or cost associated with taking part in this study.

There may be a small chance that you become distressed as a result of recalling past experiences where health care professionals did not communicate with you in a way that you wanted. If you do feel distressed and needed help, you should contact King Abdul-Aziz specialist hospital via telephone +966127310800 and you will be referred to a social worker to assess you through your distress.

(8) Are there any benefits associated with being in the study?

We cannot guarantee that you will receive any direct benefits from being in the study. However, we will be grateful for your participation.

(9) What will happen to information about me that is collected during the study?

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Study findings may be published, but you will not be individually identifiable in these publications.

(10) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study and to pass on details of the study to anyone you know who might like to participate. .

(11) What if I would like further information about the study?

When you have read this information, Reeham Ahmed Alkhaibari will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Reeham Ahmed Alkhaibari, PhD candidate, at ralk6229@uni.sydney.edu.au or via phone +61451943042 or +699556222590.

(12) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant box on the consent form at the interview or filling your details where requested on the online survey. This feedback will be in the form of a one-page lay summary. You will receive this feedback after the study is finished.

(13) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [HAP-02-T-067]. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

You could also contact the chief investigator on this project, Prof. Jennifer smith-Merry via email Jennifer.smith-merry@sydney.edu.au or the coinvestigator Dr. Rowena Forsyth via email rowena.forsyth@sydneyedu.au and for local contact Dr. Hajer Alasmari via email Hajer.alasmari@gmail.com.

This information sheet is for you to keep

APPENDIX D

Participant Information Statement (patient)

[Arabic version]

Certified Translation of Participant Information Statement
ترجمة معتمدة لبيان المعلومات للمشارك في هذه الدراسة

تخصص العلوم السُلوكية والاجتماعية الصحية
قسم العلوم الصحية
كلية الطب والصحة

THE UNIVERSITY OF SYDNEY

ABN 15 211 513 464

كبيرة الباحثين/ جينيفر سميث ميري
أستاذ مشارك
رئيسة قسم العلوم السُلوكية والاجتماعية الصحية
مديرة المركز المتخصص لأبحاث الإعاقة وسياساتها

مبنى سوزان وكيل الصحي
جامعة سيدني
نيو ساوث ويلز، ٢٠٠٦، أستراليا
الهاتف: ٣٠٤٢ ٥١٩٤ ٠٤ ٦١+
البريد الإلكتروني: ralk6229@uni.sydney.edu.au
الموقع الإلكتروني: http://www.sydney.edu.au/

كيف يمكن للمرضى المساهمة في تطوير نظام الرعاية الصحية في المملكة العربية السعودية؟
(المرضى)
بيان المعلومات للمشارك في هذه الدراسة

(١) ماذا تتضمن هذه الدراسة؟

يسر القائمون على هذه الدراسة البحثية بدعوتك للمشاركة والتي من شأنها استكشاف مدى مشاركة المريض في نظام الرعاية الصحية في المملكة العربية السعودية. كما يهمنا أن نفهم الدرجة التي يمكن أن يعمل بها الأطباء والمرضى معا من اجل تعزيز مشاركة المرضى ومساهمتهم في تطوير السياسات التي تمكن من مشاركة المريض في نظام الرعاية الصحية في المملكة.

لقد تمت دعوتك للمشاركة في هذه الدراسة بناءً على تلقيك مؤخرًا رعاية صحية في مستشفى ما في المملكة العربية السعودية، لذا كن على دراية تامة بالتفاعلات بينك كمريض وأخصائي الرعاية الصحية الذين كنت على اتصال بهم. ستساعدنا مشاركتك في اكتساب فهم أفضل لكيفية مشاركة المرضى مثلك في اتخاذ القرار بشأن خدمات الرعاية الصحية التي تتلقاها، لا سيما التعاون بين المرضى والأطباء.

يخبرك هذا البيان عن هذه الدراسة البحثية. حيث ستساعدك معرفة ما ينطوي عليه الأمر على تحديد ما إذا كنت ترغب في المشاركة في البحث ام لا. يرجى قراءة هذه الورقة بعناية وطرح أسئلة حول أي شيء لا تفهمه أو تريد معرفة المزيد عنه.

نحيطكم علما بأن المشاركة في هذه الدراسة البحثية تطوعا.

من خلال موافقتك على المشاركة في هذه الدراسة البحثية، فإنك تخبرنا أنك:
- ✓ فهمت كل ما قرأت.
- ✓ توافق على المشاركة في الدراسة البحثية على النحو المبين أدناه.
- ✓ توافق على استخدام معلوماتك الشخصية كما هو موضح.

سيتم إعطاؤك نسخة من بيان معلومات المشارك هذا للاحتفاظ به.

(٢) من يدير هذه الدراسة؟

يتم إجراء الدراسة من قبل الباحثين التالية أسماؤهم:

- ريهام أحمد الخيبري، طالبة دكتوراه في جامعة سيدني
- الأستاذ المشارك جينيفر سميث ميري، جامعة سيدني
- الدكتورة روينا فورسيث، جامعة سيدني
- الدكتورة هاجر علي الاسمري، جامعة الطائف

تجري ريهام أحمد الخيبري هذه الدراسة كمطلب أساسي لنيل درجة الدكتوراه في جامعة سيدني. سيتم هذا تحت إشراف الدكتورة جينيفر سميث ميري والدكتورة روينا فورسيث.

تم تمويل هذه الدراسة من قبل جامعة الطائف بالمملكة العربية السعودية.

(٣) ماذا ستشمل الدراسة بالنسبة للمشارك فيها؟

تتضمن هذه الدراسة خطوتين:
١) استبيان عبر الإنترنت.
٢) مقابلة.
مشاركتك في كل من الاستبيان والمقابلة اختيارية تمامًا.

ستكون مؤهلاً للمشاركة في هذه الدراسة إذا كنت تعاني من مرض السكري وتتلقى الرعاية في مركز مرضى سكري في المملكة العربية السعودية. سيُطلب منك المشاركة في استبيان ومقابلة عبر الإنترنت. يتكون الاستبيان من جزأين، الجزء الأول يطرح أسئلة ديموغرافية تشمل الجنس (ذكر ام انثى) والعمر والمستوى التعليمي والمهني والحالة الاجتماعية والصحية. كما سيتضمن الجزء الثاني من ١٦ سؤالاً لفهم تفاعلاتك الأخيرة مع مقدمي الرعاية الصحية.

إذا كنت ترغب في الاستمرار في إجراء مقابلة شخصية، فيمكنك الإشارة إلى رغبتك في القيام بذلك في نهاية الاستبيان. سنتصل بك بعد ذلك لتزويدنا بالمزيد من المعلومات حول المقابلة وإذا كنت توافق على المشاركة، فسنرتب معك موعدًا للمقابلة.

سيكون تركيز المقابلة على تجربتك وتوقع المشاركة في اتخاذ قرارات الرعاية الصحية. سيتم تسجيل المقابلة بالصوت لضمان دقة وجهات النظر الخاصة بك. لن يكون هناك مترجم لأن الباحثة ريهام الخيبري يمكنها التحدث باللغتين العربية والإنجليزية بطلاقة.

(٤) كم من وقتي ستستغرق الدراسة؟

إذا اخترت المشاركة في الدراسة، فسيُطلب منك المشاركة في استبيان عبر الإنترنت سيستغرق إكماله من ٥ إلى ١٠ دقائق تقريبًا.

إذا وافقت أيضًا على المشاركة في مقابلة، فسيستغرق إكمالها ما يقرب من ٣٠ دقيقة إلى ساعة واحدة.

(٥) من يمكنه المشاركة في الدراسة؟

ستكون مؤهلاً للمشاركة في الدراسة إذا كنت:

- ضمن الفئات العمرية ١٨سنة – ٨٠ سنة.
- متعايشا مع داء السكري من النوع الاول أو النوع الثاني

- تتلقى الرعاية في أحد مراكز السكري في المملكة العربية السعودية
- تتحدث العربية او الانجليزية

لن تكون مؤهلاً للمشاركة في الدراسة إذا كنت:
- حالة ضعف في التواصل مع الاخرين مثل ضعف السمع أو النطق حيث لا يتوفر لدينا تمويل للترجمة.

(٦) هل يجب أن اشارك في هذه الدراسة؟ هل يمكنني الانسحاب منها بمجرد أن ابدأ؟

أنه امر اختياري تمامًا ان تكون ضمن هذه الدراسة ولا يلزمك المشاركة فيها. علاوة على ذلك، فإن قرارك بالمشاركة من عدمه لن يؤثر على علاقتك الحالية أو المستقبلية بالباحثين أو أخصائي الرعاية الصحية أو جامعة سيدني أو جامعة الطائف.

بالنسبة للاستبيان عبر الإنترنت، يعد إرسال الاستبيان المكتمل مؤشراً على موافقتك على المشاركة في الدراسة. يمكنك سحب ردودك في أي وقت قبل إرسال الاستبيان. فبمجرد إرساله، لا يمكنك سحب ردودك لأنها مجهولة الهوية، وبالتالي، لن نتمكن من تحديد أي منها يخصك.

بالنسبة للمقابلة، تعتبر المشاركة في المقابلة اختيارية تمامًا، ويمكنك أيضا رفض الإجابة على أي أسئلة لا ترغب في الإجابة عليها أثناء المقابلة. بعد اكتمال المقابلة، سيكون لديك أسبوعان للانسحاب ولكن لن تكون قادرًا على الانسحاب بعد ذلك الوقت حيث سيتم مسح التسجيلات وإخفاء البيانات.

(٧) هل هناك أي مخاطر أو تكاليف مرتبطة بالمشاركة في الدراسة؟

بصرف النظر عن إعطائك الوقت الكافي للمشاركة في هذه الدراسة البحثية، لا نتوقع وجود أي مخاطر أو تكاليف مرتبطة بالمشاركة.

قد تكون هناك فرصة ضئيلة لأن تصاب بالضيق نتيجة لتذكر التجارب السابقة حيث لم يتواصل أخصائي الرعاية الصحية معك بالطريقة التي تريدها. إذا كنت تشعر بالحزن وتحتاج إلى مساعدة، يجب عليك الاتصال بمستشفى الملك عبد العزيز التخصصي عبر الهاتف (٩٦٦١٢٧٣١٠٨٠٠+) وسيتم تحويلك إلى أخصائي اجتماعي لتقييم حالتك.

(٨) هل توجد أي فوائد مرتبطة بالمشاركة في الدراسة؟

لا يمكننا ضمان حصولك على أي مزايا مباشرة من مشاركتك في هذه الدراسة. ومع ذلك، سنكون ممتنين لمشاركتك.

(٩) ماذا سيحدث للمعلومات الخاصة بي التي تم جمعها أثناء الدراسة؟

من خلال تقديم موافقتك، فإنك توافق على قيامنا بجمع معلومات شخصية عنك لأغراض هذه الدراسة البحثية. سيتم استخدام معلوماتك فقط للأغراض الموضحة في بيان معلومات المشارك هذا، ما لم توافق على خلاف ذلك.

قد يتم نشر نتائج الدراسة، لكن لن يتم التعرف عليك بشكل فردي في هذه النتائج المنشورة.

(١٠) هل يمكنني إخبار الآخرين عن الدراسة؟

نعم، فنحن نرحب بك لإخبار الآخرين عن الدراسة ونقل تفاصيل الدراسة إلى أي شخص تعرفه قد يرغب في المشاركة.

(١١) ماذا لو كنت أرغب في مزيد من المعلومات حول الدراسة؟

عندما قرأتك للمعلومات المتاحة في هذا البيان، فإن ريهام أحمد الخيبري ستكون متاحة لمناقشة هذا البيان بشكل اوسع والإجابة على أي أسئلة قد تطرأ على ذهنك. إذا كنت ترغب في معرفة المزيد في أي مرحلة أثناء هذه الدراسة، فلا تتردد في الاتصال بـ ريهام أحمد الخيبري، طالبة الدكتوراة، على ralk6229@uni.sydney.edu.au أو عبر الهاتف (٩٦٦٥٥٦٢٢٢٥٩٠+) أو (٦١٤٥١٩٤٣٠٤٢+).

(١٢) هل سيتم إخباري بنتائج الدراسة؟

لديك الحق في تلقي ملاحظات حول النتائج الإجمالية لهذه الدراسة. يمكنك إخبارنا برغبتك في تلقي التعليقات عن طريق تحديد المربع ذي الصلة في نموذج الموافقة في المقابلة أو ملء التفاصيل الخاصة بك عند الطلب في الاستبيان عبر الإنترنت. ستكون هذه الملاحظات في شكل ملخص تخطيطي من صفحة واحدة. سوف تتلقى هذه الملاحظات بعد الانتهاء من هذه الدراسة.

(١٣) ماذا لو كان لدي شكوى أو أي مخاوف بشأن الدراسة؟

تتم مراجعة الأبحاث التي تشمل المقيمين في أستراليا من قبل مجموعة مستقلة من الأشخاص تسمى لجنة أخلاقيات البحث البشري (HREC). تمت الموافقة على الجوانب الأخلاقية لهذه الدراسة من قبل HREC بجامعة سيدني [أدخل رقم البروتوكول بمجرد الحصول على الموافقة]. كجزء من هذه العملية، اتفق القائمون على هذه الدراسة البحثية على إجراءها وفقا للبيان الوطني للسلوك الأخلاقي في البحث البشري (٢٠٠٧). تم تطوير هذا البيان لحماية الأشخاص الذين يوافقون على المشاركة في الدراسات البحثية.

إذا كنت قلقا بشأن الطريقة التي يتم بها إجراء هذه الدراسة أو كنت ترغب في تقديم شكوى إلى شخص مستقل عن الدراسة، فيرجى الاتصال بالجامعة باستخدام التفاصيل الموضحة أدناه. يرجى ذكر عنوان الدراسة ورقم البروتوكول.

مدير إدارة الأخلاقيات بجامعة سيدني:

- **الهاتف**: ٨١٧٦ ٨٦٢٧ ٢ ٦١+
- **البريد الإلكتروني**: human.ethics@sydney.edu.au
- **الفاكس**: ٨١٧٧ ٨٦٢٧ ٢ ٦١+

يمكنك أيضا الاتصال بكبيرة الباحثين في هذا المشروع
الأستاذ المشارك/ جنيفر سميث ميري عبر البريد الإلكتروني Jennifer.smith-merry@sydney.edu.au
أو نائبتها في هذه الدراسة/ د. روينا فورسيث عبر البريد الإلكتروني rowena.forsyth@sydneyedu.au

للاتصال في المملكة العربية السعودية، يمكنك إرسال بريد إلكتروني إلى د. هاجر الاسمري على Hajer.alasmari@gmail.com

يمكنك الاحتفاظ بهذه الورقة

I, SAMER SALEH EBRAHIM HAKAMI, a National Accreditation Authority for Translators and Interpreters [NAATI] certified translator no. CPN6WO03I hereby certify that I have translated this document from English language into Arabic language on 15 Aug. 2021.

APPENDIX E

Participant Information Statement

(Healthcare providers)

THE UNIVERSITY OF SYDNEY

Discipline of Behavioural and Social Sciences in Health
School of Health Science
Faculty of Medicine and Health

ABN 15 211 513 464

CHIEF INVESTIGATOR Jennifer Smith-Merry
Associate Professor
Head of Discipline Behavioural and Social Sciences in Health
Director of the Centre for Disability Research and Policy

Susan Wakil Health Building
The University of Sydney
NSW 2006 AUSTRALIA
Telephone: +61 045193042
Email: ralk6229@sydney.edu.au
Web: http://www.sydney.edu.au

HOW CAN PATIENTS CONTRIBUTE TO DEVELOPING THE HEALTHCARE SYSTEM IN SAUDI ARABIA?
Healthcare professionals
PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in a research study exploring patient involvement in the healthcare system in Saudi Arabia. We want to understand the degree to which physicians can work with patients to enhance patient involvement and contribute to the development of policies guiding patient involvement in the healthcare system in the Kingdom**.**

You have been invited to participate in this study because you are a health care practitioner providing care to patients in Saudi Arabia. Your participation will help us to gain better understanding of your experience of the involvement of patients in health care decision making. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving your consent to take part in this study you are telling us that you:
- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

The study is being carried out by the following researchers:
- Reeham Ahmed Alkhaibari, PhD candidate at the University of Sydney.
- Associate Professor Jen Smith-Merry, The University of Sydney
- Dr Rowena Forsyth, The University of Sydney
- Dr Abulellah Althobaity, Taif University

Reeham Ahmed Alkhaibari is conducting this study as the basis for the degree of *PhD* at The University of Sydney. This will take place under the supervision of the investigators named above.

This study is being funded by Taif University, Kingdom of Saudi Arabia.

(3) What will the study involve for me?

You will be asked to take a part in an online questionnaire. The online questionnaire will consist of three parts, the first part asks for general demographic and social data, education, practice experience, experience of communication-related training, knowledge of patient centered care, and time spent interacting with patients. Other questions focus on patient-centred care and work environment.

(4) How much of my time will the study take?

If you choose to participate in the study, you will be asked to complete an online questionnaire that consists of three sections, which will take you approximately 15 minutes to complete.

(5) Who can take part in the study?

You will be eligible to participate in the study if you meet the following criteria:

- You are a health care provider
- You provide care within a hospital in Saudi Arabia

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you are not required to take apart in the study. Your decision whether to participate or not will not affect your current or future relationship with the researchers, the University of Sydney, King Abdul-Aziz specialist hospital in Taif city or Taif University.

Submitting your completed questionnaire is an indication of your consent to participate in the study. You can withdraw your responses any time before you have submitted the questionnaire. Once you have submitted it, your responses cannot be withdrawn because they are anonymous and we will not be able to tell which responses are yours.

(7) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

There may be a small chance that you become distressed as a result of recalling past experiences where health care professionals did not communicate with you in a way that you wanted. If you do feel distressed and needed help, you should contact King Abdul-Aziz specialist hospital via telephone +966127310800 and you will be referred to a social worker to assess you through your distress.

(8) Are there any benefits associated with being in the study?

We cannot guarantee that you will receive any direct benefits from being in the study. However, we will be grateful for your participation.

(9) What will happen to information about me that is collected during the study?

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Study findings may be published, but you will not be individually identifiable in these publications.

(10) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study. You can pass on details of the study to your fellow practitioners if you feel that they would be interested in participating in the study.

(11) What if I would like further information about the study?

When you have read this information, Reeham Ahmed Alkhaibari will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Reeham Ahmed Alkhaibari, PhD candidate, at ralk6229@uni.sydney.edu.au or via phone +61451943042 or +699556222590.

(12) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant box on the survey and providing your email address. This feedback will be in the form of a one-page lay summary. You will receive this feedback after the study is finished.

(13) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [*HAP-02-T-067].* As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007).* This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

You could also contact the chief investigator on this project, Prof. Jennifer Smith-Merry via email Jennifer.smith-merry@sydney.edu.au or the coinvestigator Dr. Rowena Forsyth via email rowena.forsyth@sydneyedu.au
For a local contact in Saudi Arabia, you can contact Dr. Abulellah Althobaity via email a.thobaity@tu.edu.sa

APPENDIX F

Patient Informed Consent

[English version]

THE UNIVERSITY OF SYDNEY

Discipline of Behavioural and Social Sciences in Health
School of Health Science
Faculty of Medicine and Health

ABN 15 211 513 464

CHIEF INVESTIGATOR Jennifer Smith-Merry
Associate Professor
Head of Discipline Behavioural and Social Sciences in Health
Director of the Centre for Disability Research and Policy

Susan Wakil Health Building
The University of Sydney
NSW 2006 AUSTRALIA
Telephone: +61 045193042
Email: ralk6229@sydney.edu.au
Web: http://www.sydney.edu.au/

HOW CAN PATIENS CONTRIBUTE TO DEVELOPING THE HEALTHCARE SYSTEM IN SAUDI ARABIA?

PATIENTS CONSENT FORM

I, ..., agree to take part in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Statement and have been able to discuss my involvement in the study with the researchers if I wished to do so.
- The researchers have answered any questions that I had about the study and I am happy with the answers.
- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney now or in the future.
- I understand that I can withdraw from the study at any time.
- I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study. I also understand that I may refuse to answer any questions I don't wish to answer.
- I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
- I understand that the results of this study may be published, and that publications will not contain my name or any identifiable information about me

I consent to:

- **Audio-recording** YES ☐ NO ☐
- **Being contacted to participate in an interview** YES ☐ NO ☐

I would like to review my interview transcripts YES ☐ NO ☐

I would like to receive feedback about the overall results of this study YES ☐ NO ☐

If you answered **YES**, please indicate your preferred form of feedback and address:

☐ Postal: _____

_____

☐ Email: _____

.....
Signature

.....
PRINT name

.....
Date

APPENDIX G

PATIENT INFORMED CONSENT

[Arabic version]

Certified Translation of Patients Consent Form
ترجمة معتمدة لاستمارة موافقة المرضى

تخصص العلوم السُلوكية والاجتماعية الصحية
قسم العلوم الصحية
كلية الطب والصحة

THE UNIVERSITY OF SYDNEY

ABN 15 211 513 464

كبيرة الباحثين/ جينيفر سميث ميري
أستاذ مشارك
رئيسة قسم العلوم السُلوكية والاجتماعية الصحية
مديرة المركز المتخصص لأبحاث الإعاقة وسياساتها

مبنى سوزان وكيل الصحي
جامعة سيدني
نيو ساوث ويلز، ٢٠٠٦، أستراليا
الهاتف: ٣٠٤٢ ٥١٩٤ ٠٤ ٦١+
البريد الإلكتروني: ralk6229@uni.sydney.edu.au
الموقع الإلكتروني: http://www.sydney.edu.au/

كيف يمكن للمرضى المساهمة في تطوير نظام الرعاية الصحية في المملكة العربية السعودية؟

استمارة موافقة المرضى

أنا، ..... ، اوفق على المشاركة في هذه الدراسة البحثية.

عند منح موافقتي، أصرح بما يلي:

- أفهم الغرض من الدراسة، وما سيُطلب مني القيام به، وأي مخاطر او منافع متضمنة.
- لقد قرأت بيان معلومات المشارك وتمكنت من مناقشة مشاركتي في الدراسة مع الباحثين عند رغبتي بذلك.
- أجاب الباحثون على أي أسئلة لدي حول الدراسة وأنا سعيد بإجاباتهم.
- أفهم أن وجودي في هذه الدراسة طوعي تمامًا ولست مضطرًا للمشاركة. لن يؤثر قراري في المشاركة في الدراسة على علاقتي بالباحثين أو أي شخص آخر في جامعة سيدني الآن أو في المستقبل.
- أفهم أنه يمكنني الانسحاب من الدراسة في أي وقت.
- أفهم أنني قد أوقف المقابلة في أي وقت إذا لم أرغب في الاستمرار، وأنه ما لم أذكر خلاف ذلك، سيتم مسح أي تسجيلات ولن يتم ادراج المعلومات المقدمة في الدراسة. أفهم أيضًا أنني قد أرفض الإجابة على أي أسئلة لا أرغب في الإجابة عليها.
- أفهم أن المعلومات الشخصية الخاصة بي التي تم جمعها خلال فترة الدراسة سيتم تخزينها بشكل آمن وسيتم استخدامها فقط للأغراض التي وافقت عليها. أفهم أن المعلومات الخاصة بي لن يتم مشاركتها مع الآخرين إلا بإذن مني، باستثناء ما يقتضي القانون.
- أفهم أنه قد يتم نشر نتائج هذه الدراسة، وأن المنشورات لن تحتوي على اسمي أو أي معلومات يمكن التعرف عني من خلالها.

أوافق على:

- **التسجيل الصوتي** نعم ☐ لا ☐
- **يتم الاتصال بي للمشاركة في مقابلة** نعم ☐ لا ☐

أرغب في مراجعة محاضر المقابلة الخاصة بي نعم ☐ لا ☐

أرغب في تلقي تعليقات حول النتائج الإجمالية لهذه الدراسة نعم ☐ لا ☐

إذا كانت إجابتك بنعم، فيرجى الإشارة إلى النموذج المفضل لديك للتعليقات والعنوان:

☐ العنوان : _____

_____

☐ البريد الالكتروني: _____

.....

التوقيع

.....

اسم الموقع اعلاه

.....

التاريخ

I, SAMER SALEH EBRAHIM HAKAMI, a National Accreditation Authority for Translators and Interpreters [NAATI] certified translator no. CPN6WO03I hereby certify that I have translated this document from English language into Arabic language on 15 Aug. 2021.